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PREDICTORS OF MAMMOGRAPHY SCREENING USE

AMONG WOMEN WITH MS

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PREDICTORS OF MAMMOGRAPHY SCREENING USE AMONG WOMEN WITH MS

by

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Dissertation

Presented to the Faculty of the Graduate School of

The University of Texas at Austin

in Partial Fulfillment

of the Requirements

for the Degree of

Doctor of Philosophy

The University of Texas at Austin

December 2013

Dedication

To my dear mother Galla Esperanza Wiess de Santa Anna for her endless love and support.

Acknowledgements

I would like to acknowledge the NIH, NINR grant R01NR003195 (NIH, NINR) and the Diversity Training Supplement R01NR003195-14S under Dr. Alexa Stuifbergen's ongoing longitudinal study on health promotion and quality of life in chronic illness.

My deepest gratitude goes to my wonderful advisor and mentor, Dean Alexa Stuifbergen for providing extensive knowledge, wisdom, and guidance during this transformative process. I thank her for providing me the invaluable opportunity to be a member of her research team as a research trainee where I was able to gain experience as a researcher. Most of all, I appreciate all her boundless encouragement, compassion, and patience. As a role-model and mentor, she exemplified the research scientist, teacher, and mentor, we should all aspire to become.

I express my gratitude to my committee members, Dr. Heather Becker, Dr. Adama Brown, Dr. Gayle Timmerman, and Dr. JoAnn Thierry for sharing all their expertise and knowledge related to the research process. I appreciate all their time and dedication to helping me achieve my goals as a scientist.

I thank Dr. Carole Taxis for all her mentoring in teaching and for her continual support and motivation. I appreciate her assuring me that all things are possible.

I would like to thank Rudy Ortiz for all his help throughout in the program. I thank Bob Penman at the Graduate School for his extensive help formatting this dissertation.

My heartfelt thanks goes to my dear friends Shalonda Horton, Mandeep Kaur, Janiece Walker, Linda Murphy, Elizabeth Perry, Vicki Kulberg, Janet Morrison, Lynn

Chen, and Hsiu-Rong Cheng for all their loving support and prayers. To my writing partners, thank you for being my motivators and my rock. I thank Nancy Hazen-Swann for all her words of wisdom and for encouraging me to pursue my Ph.D. A special thanks goes to my dear friend Mary Pat Smith for always being my inspiration, for teaching me perseverance and faith in myself and in God in the face of obstacles.

Most of all, I am forever blessed for my dear family, my children, Brian, Christopher, Sandra, Maria Teresa, and Katharine for all their help, but especially for their unconditional patience and love. I thank them for their inspiring words of encouragement.

Finally, I am forever grateful to God and Our Lord Jesus Christ for giving me this opportunity to do His work.

Predictors of Mammography Screening Use Among Women With MS

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Breast cancer is a leading cause of mortality among women in the United States. Women with chronic disabling conditions such as multiple sclerosis (MS) are less likely to participate in routine mammography screening than women without disabilities due to multiple barriers. Underuse of mammography screening may lead to a diagnosis of a later stage breast cancer and consequently higher breast cancer mortality rate. This study examined the influence of several factors including, severity of MS-related functional limitations, demographic characteristics, family history of breast cancer, beliefs related to mammography screening and breast cancer, and personal resources on usual screening mammography in a sample of women with MS. The conceptual framework guiding this study was synthesized from The Explanatory Model of Health Promotion and Quality of Life in Chronic and Disabling Conditions and the Health Belief Model.

Data from an ongoing longitudinal study (R01NR003195) focused on health promotion of persons with MS were combined with primary data for this prospective descriptive correlational study. The nonprobability sample consisted of 274 women ages 39-85 years who were primarily White (92%), married (66.1%), and unemployed (64.1%)

with a 22 year average length of diagnosis with MS. Data were collected over two years using a mailed survey. Descriptive statistics and hierarchical logistic regression analyses were used to address the research questions.

The annual mammography rate in this sample was 62%. Perceived susceptibility to breast cancer (AOR = 3.0, $p < .05$), family history (AOR = 2.5, $p < .05$), economic adequacy (AOR = 1.6, $p < .05$), and perceived barriers to mammography (AOR = .98, $p < .05$) significantly predicted mammography use, adjusted for severity of functional limitations. Though severity of limitations was negatively associated with mammography, it was not a significant predictor in the overall model.

These findings suggest that for women with chronic disabling conditions, health beliefs, family history, and personal resources influence mammography screening. Clinicians need to continue to eliminate the barriers to mammography screening to improve screening and reduce overall breast cancer mortality rate in this vulnerable population.

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Chapter 1: Introduction

In 2005, the Surgeon General announced a *Call to Action* to improve the health and wellness of individuals with disabilities (United States Department of Health and Human Services [USDHHS], 2005). The means to achieve this objective is to address those factors contributing to the disparities in health and health care in this vulnerable population. Research evidence suggests that there continues to be disparities in health care utilization for women with chronic disabling conditions (WWCDC) (Smeltzer, 2006; Smith, 2008). Specifically, WWCDC are more likely to delay needed medical care despite having a usual source of care (Chevarley, Thierry, Gill, Ryerson, & Nosek, 2006; Parish & Ellison-Martin, 2007; Parish & Huh, 2006) and are less likely than their non-disabled counterparts to engage in preventive screenings, including mammography screening (Courtney-Long, Armour, Frammartino, & Miller, 2011; Ramirez, Farmer, Grant, & Papachristou, 2005; Wei, Findley, & Sambamoorthi, 2006).

Although there have been recent changes in the guidelines for initiating mammography screening, research continues to provide evidence that early detection through breast cancer screening, which includes mammography screening, clinical breast exams, and to some degree breast self-examination, reduces the overall mortality rate from breast cancer, a leading cause of death of U.S. women (American Cancer Society [ACS], 2011; U.S. Preventive Services Task Force [USPSTF], 2009; Tabar et al., 2003). Breast cancer screening is particularly salient for WWCDC since they also are more likely to be older and obese, which are known breast cancer risk factors (ACS, 2011; Chevarley et al., 2006). In some instances among women with multiple sclerosis (MS), there may be a slightly elevated chance of developing breast cancer for reasons not yet understood (Nielsen et al., 2005). Furthermore, there is evidence that WWCDC are more

likely to be diagnosed at a later, less treatable stage, which translates to a higher breast cancer mortality rate (McCarthy et al., 2007; McCarthy et al., 2006; Roetzheim & Chirikos, 2002).

In the general population, several studies have identified factors that significantly predict mammography use. These factors include some demographic characteristics (age, income, insurance coverage, and family history of breast cancer) as well as psychosocial factors (social support and beliefs about breast cancer screening) (Scheuler, Chu, & Smith-Bindman, 2008). Compared to extensive literature focused on the general population or other underserved populations such as minority women, there is a lack of extant literature on factors contributing to mammography use among WWCDC. In particular, little is known about the influence of psychosocial factors (e.g. social support) and health beliefs related to mammography screening on routine mammography use for WWCDC.

HEALTH, WELL-BEING, HEALTH PROMOTION, AND MAMMOGRAPHY SCREENING

The concept of health as well-being originated from the World Health Organization (WHO, 2003) and is defined as " a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" (Saylor, 2004 p. 100). This holistic definition of health is a drastic departure from the traditional philosophical underpinnings guiding the medical model that historically emphasized the physical component and as a separate entity, the mental component of health (Pender, Murdaugh, & Parsons, 2002). Pender et al. (2002) defined health and well-being as "actualization of inherent and acquired human potential through goal directed behavior, competent self-care, and satisfying relationships with others, while adjustments are made to maintain structural integrity and harmony with relevant environments" (p. 22).

Inherent in this definition is the notion that health is on a continuum and can be achieved within the context of having a chronic disabling condition.

The paradigm shift in the definition of health as well-being provides the conceptual underpinnings of health promotion. Pender et al. (2002) define health promotion as "increasing the level of well-being and self-actualization of a given individual or group" (p. 34). Behavior that promotes health would therefore include those activities "motivated by the desire to increase well-being and actualize human potential" (Pender et al., 2006, p. 7).

Historically, the predominant medical perspective has categorized health screening, including mammography screening, as a preventive or protective health behavior. Pender, Murdaugh, and Parsons (2006) differentiate health promotion from health protection in that the motivation behind the behavior is to "maximize wellness" and not to prevent a disease and the consequences of this disease. One could argue therefore that the subtle difference between health promotion and health protection lies in the motivation behind the health behavior. This logic would allow health behaviors such as exercising and healthy eating to be simultaneously health "promoting" and health "protective" depending on the individual's motivation. For example, the individual who has cardiovascular disease may exercise and modify his/her diet as a health protective measure or disease management. However, if the underlying motive of "maximizing wellness" underlies the motivation in his/her behavior, then exercising and eating well become health "promoting" behaviors. This logic can also be used to support the argument that mammography screening is a health promoting as well as a health protective behavior. Furthermore, Pender and colleagues (2006) posit that for health protection or disease prevention, the behavior centers around preventing an illness and its consequences. In the case of breast cancer, unlike tetanus, mumps, measles, and rubella,

although there are ways to reduce one's risk, there are no definitive methods to "prevent" breast cancer from occurring. For this reason, for the purposes of this paper, mammography screening will be classified as a health promoting behavior because early detection would be an action intended to maximize one's health within the context of the disease.

BACKGROUND AND SIGNIFICANCE

Breast cancer continues to be a leading cause of death among U.S. women with an estimated 232,340 new cases and 39,620 deaths expected in 2013 (ACS, 2013). Despite the recent debate surrounding screening initiation and frequency, mammography continues to be validated as an effective tool to detect breast cancer at an early more treatable stage (ACS, 2013; Tabar et al., 2003). Studies suggest that women with chronic and disabling conditions are less likely to engage in preventive screening, including mammography screening, compared to women with no disabilities (Courtney-Long et al. 2011; Iezzoni, McCarthy, Davis, Harris, & O'Day, 2001; Iezzoni, McCarthy, Davis, & Siebens, 2000; Schootman & Jeffe, 2003; Smith, 2008; Wei et al., 2006). In the years between 2001–2005, only slightly over half (54.9%) of women, 50 years and older with severe limitations compared with 75.4% of women without disability reported receiving mammograms in the last two years (USDHHS, 2008).

For WWCDC and women in the general population significant predictors of mammography screening include demographic characteristics (age and education) and access-related factors such as financial status (including insurance), and usual source of care (Chevarley et al., 2006; Scheuler et al., 2008). Additionally, in the general population, psychosocial factors such as perceived social support, beliefs regarding perceived benefits and barriers to mammography screening, and perceived susceptibility

of developing breast cancer significantly predict regular mammography screening (Champion et al., 2008; Champion et al., 2004; Lee-Lin et al., 2008; Fite, Frank, & Curtin, 1996; Jackson, 2006).

Several factors may contribute to the disparity in mammography screening in WWCDC including financial, environmental, and physical barriers (functional limitations) experienced in this population (Todd & Stuifbergen, 2012). Compared to women with no disabilities, WWCDC are more likely to be older, have less education, lower income, public insurance, and are more likely to delay needed medical care despite having a usual source of care (U.S. Census Bureau, 2006). Furthermore, WWCDC face unique obstacles related to building inaccessibility, mammography equipment that does not accommodate women unable to stand, and lack of transportation (Mele, Archer, & Pusch, 2005; Smeltzer, Sharps-Hopko, Ott, Zimmermaná, & Duffin, 2007; Todd & Stuifbergen, 2011). Faced with inherent competing demands of a chronic illness combined with a potential breast cancer diagnosis, WWCDC may feel they already "have enough to deal with" (*No Más*) and consequently resist getting mammograms (Todd & Stuifbergen, 2011).

Women living with MS, a progressive autoimmune neurological disease characterized by an inflammatory and sclerosing process of the white matter in the central nervous system (CNS) and demyelination of the axonal nerve sheath (Gulick, 1998; National Multiple Sclerosis Society [NMSS], 2012; Rao, Leo, Bernardin, & Unverzagt, 1991), can serve as exemplars for WWCDC. MS has a wide array of physical, psychological, and cognitive manifestations that, like other chronic disabling conditions (e.g., osteoarthritis), results in varying levels of functional limitations and disability. The clinical manifestations of MS are dependent on the location of the neural damage and may include muscle spasticity, weakness and numbness, bowel and bladder dysfunction,

sexual dysfunction, visual disturbances (optic neuritis and double vision), cognitive impairment, fatigue, and depression. Multiple sclerosis is clinically variable and is classified into four different types: relapsing-remitting, primary progressive, secondary progressive, and progressive-relapsing. Relapsing-remitting is the most common type of MS (80%) and is characterized by episodic exacerbations followed by complete recovery. Approximately 50% of those initially diagnosed with relapsing-remitting MS will move to secondary-progressive MS within 10 years of the initial diagnosis (Noseworthy, Luchinetti, Rodrigues, & Weinshenker, 2000). The trajectory of severity of limitations is variable and is related to a number of factors such as age of onset, interval between relapses, residual deficit after relapses, greater number of systems involved, and gender (Amato, Ponziani, Batolozzi, & Siracusa, 1999; Pittock et al., 2004).

Multiple sclerosis primarily affects women; at least two to three times as many women are diagnosed with MS as men. The peak onset for MS is 30 years of age and it is most frequently diagnosed between the ages of 20 to 40 (NMSS, 2012). Therefore, MS is a disease that affects younger women who may be at the peak of their family and employment responsibilities. Likewise, with respect to women's health care needs, this is a time of life when women need to be actively attending to preventive screening (PAP test, clinical breast exams, mammography) (ACS, 2013). Unfortunately, women with MS may find it challenging to maintain the recommended screening regime due to the multiple competing demands characteristic of living with a chronic disabling condition (Todd & Stuifbergen, 2011). Routine mammography screening is especially important for women with MS as there is some evidence for an association between MS and a slightly higher risk of developing breast cancer (Nielsen et al., 2005; Noseworthy et al., 2000). The cause of this elevated risk for breast cancer is unknown, but it is speculated that the drug modalities reduce the proliferation of T cells (interferon beta-1a and b) and may in

turn stimulate neutralizing antibodies (Noseworthy et al., 2000). Based on the potential elevated risk for breast cancer, routine mammography screening is especially important in this population.

In sum, there is evidence that routine mammography use may be influenced by factors unique to WWCDC (Todd & Stuifbergen, 2012). Studies of mammography screening for women without disabling conditions have identified positive and negative predictors of mammography use, including the psychosocial factors (social support) and health beliefs about breast cancer screening (Scheuler et al., 2008). Little is known about how personal resources (e.g., social support and economic adequacy) and health beliefs influence routine mammography use for women with varying severity of MS-related functional limitations. This study will provide some valuable information that may help inform strategies to eradicate prevailing disparities in mammography use and other preventive care among WWCDC.

PURPOSE

The purpose of this prospective descriptive study was to examine the influence of severity of MS-related functional limitations, demographic characteristics (age and education), family history of breast cancer, health beliefs related to mammography screening (perceived benefits, barriers, and susceptibility to breast cancer), and personal resources (social support, economic adequacy, and insurance status) on the likelihood of annual mammography screening use in a sample of women with MS.

RESEARCH QUESTIONS

The specific research questions are:

1. What is the percentage of regular (usual) mammography screening (every year) in this sample of women with MS?

2. What are the relationships among contextual factors (MS-related functional limitations, age, and education), family history of breast cancer, health beliefs related to mammography (perceived benefits, barriers and susceptibility to breast cancer), personal resources (social support, economic adequacy, and insurance coverage), and annual mammography use among this sample of women with MS?

3. What are the significant predictors among the independent variables of contextual factors (MS-related functional limitations, age, education), family history of breast cancer, health beliefs related to mammography (perceived benefits, barriers and susceptibility to breast cancer), and personal resources (social support, economic adequacy, and insurance coverage) for the dependent variable of annual mammography screening use among this sample of women with MS?

   a. Among these factors, which factor most contributes to the likelihood of annual mammography use among this sample of women with MS?

   b. Among these factors, what are the significant predictors for annual mammography use after controlling for severity of MS-related functional limitations and demographic characteristics (age and education) among this sample of women with MS?

CONCEPTUAL MODEL

The conceptual model used for this proposed study, the Model for Breast Cancer Screening for WWCDC, synthesized concepts from the Health Belief Model (HBM)

(Rosenstock, 1974) and the Explanatory Model of the Quality of Life for Persons with Chronic Disabling Conditions (Stuifbergen, Seraphine, & Roberts, 2000). The HBM constructs used for this study are the following: perceived benefits, barriers of mammography, and perceived susceptibility to breast cancer. The constructs taken from the model by Stuifbergen and colleagues (2000) are the following: severity of MS related functional limitations, perceived personal resources, and mammography use (as a health promoting behavior).

The HBM, an individual-level model, developed in the 1950's by social psychologists, is a conceptual framework that has been widely used to explain health behavior, including preventive screening (Hochbaum, 1958; Rosenstock, 1974). The HBM is considered a value expectancy theory based on the premise that "behavior is a function of the subjective *value* of an outcome and of the subjective probability, or *expectation,* that a particular action will achieve that outcome" (Champion & Skinner, 2008, p. 46).

The six constructs of the revised HBM include perceived susceptibility, perceived seriousness, perceived benefits over barriers, cues to action, and self-efficacy (Rosenstock, Strecher, & Becker, 1988). According to the HBM, an individual's behavior is dependent on whether they perceive that they are susceptible to a condition and their perception that the condition is serious. Furthermore, in order for the individual to take action to prevent the condition, they must perceive that the benefits (to prevent the illness) of performing the health action outweigh the barriers (costs). In addition, the individual may be exposed to triggers that potentiate action such as environmental cues (e.g. media). Self-efficacy (perceiving they are able to perform the health behavior) will also influence the likelihood of the health behavior (Bandura, 1977). Therefore, in order for a woman to engage in mammography screening, a woman must first perceive that she

is susceptible to developing breast cancer and perceive the seriousness of this disease, which in turn, generates a perceived threat. In addition, she must perceive that the benefits of getting a mammogram outweigh the barriers (e.g., costs and risks).

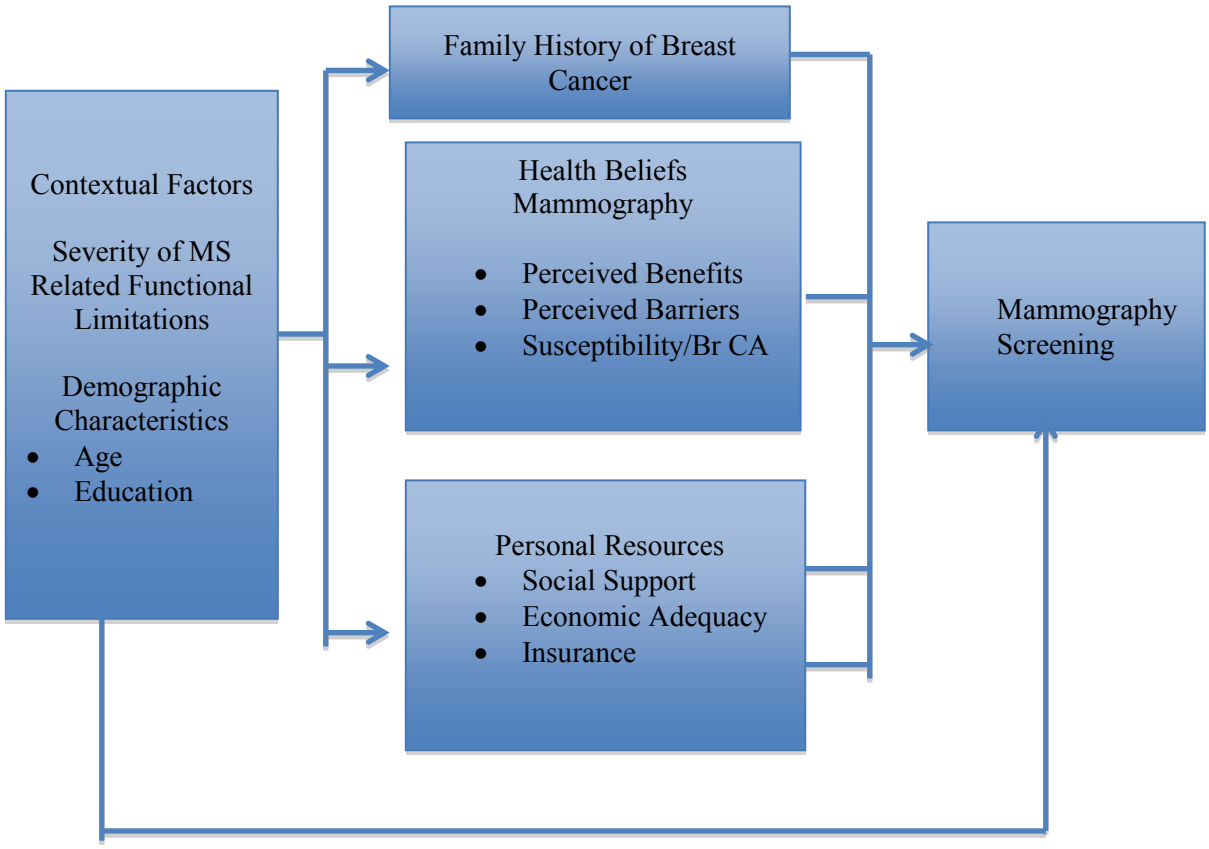
The HBM has been widely used to predict breast cancer screening (including mammography, CBE, and BSE) across multiple, diverse populations (Champion & Skinner, 2003; Pasick & Burke, 2008; Soskolne, Marie, & Manor, 2007; Yarbrough & Braden, 2001). For example, a number of studies showed that when women perceive low susceptibility to breast cancer, more barriers (e.g., fear of pain) than benefits of getting a mammogram (early detection of breast cancer, overall wellness), their intention of getting a mammogram is diminished (Champion & Skinner, 2003; Champion et al., 2008; Champion & Scott, 1997; Champion & Skinner, 2003; Clemow et al., 2000; Katapodi, Dodd, Lee, Facione, 2009; Katapodi, Lee, Facione, & Dodd, 2004). Although there is evidence that the HBM constructs are able to explain adherence to mammography, Yarbrough and Braden (2001) found that the variance explained for screening by one or a combination of HBM constructs was relatively low, ranging from 15%–27%. Similarly, one study reported explained variances of 9% and 13% for African American and Caucasian women for screening adherence (Vadaparampil, Champion, Miller, Menon, & Skinner, 2003). Strecher and Rosenstock (2002) found that of the HBM constructs, perceived barriers and perceived susceptibility have been shown to have the greatest ability to predict mammography screening adherence, with barriers having the most predictive power. Low explained variance suggests that the HBM used alone does not sufficiently predict mammography use for WWCDC. Therefore, the concepts from the Explanatory Model of Health Promotion and Quality of Life in Chronic and Disabling Conditions (Stuifbergen et al., 2000) were added to create the final conceptual model for mammography use among WWCDC.

Several concepts from the Stuifbergen et al. (2000) Explanatory Model of Health Promotion and Quality of Life in Chronic Disabling Conditions were included in the Breast Cancer Screening Model for WWCDC. This Explanatory Model was developed by synthesizing multiple qualitative and quantitative research findings on persons with chronic disabling conditions including MS (Stuifbergen & Becker, 1994; Stuifbergen & Rogers, 1997). This model incorporates, Pender's Health Promotion Theory (HPM) (2006) and Bandura's Self-Efficacy Theory (Bandura, 1977).

The Stuifbergen et al. (2000) model has been tested extensively with persons with MS to explain how explanatory factors (contextual factors [i.e. MS-related functional limitations], perceived personal resources, barriers, self-efficacy, acceptance, and health-promoting behaviors) influence the disablement process and quality of life of persons with chronic disabling conditions. The constructs, personal resources, barriers, and health-promoting behaviors are from the HPM (Pender, 2006). In Stuifbergen's model, the outcome variable, quality of life, is influenced by the interaction between severity of illness (limitations), perceived barriers, personal resources, self-efficacy, degree of acceptance (adjustment to illness), and health-promoting behaviors. The primary contextual factor, severity of illness, is directly related to perceived barriers, personal resources and quality of life (Stuifbergen et al., 2000). The path from severity of illness to health-promoting behaviors is influenced by the amount of perceived barriers, personal resources, self-efficacy and the degree to which a person has adjusted to their limitations (Stuifbergen et al., 2000). Finally, engaging in health promoting behaviors has a direct effect on quality of life.

In the Breast Cancer Screening Model for WWCDC (Figure 1), severity of MS-related functional limitations and demographic characteristics (age and education)

Figure 1. Conceptual Model



are the personal or contextual factors. According to this model, the likelihood of engaging in regular mammography screening (every 1–2 years) is influenced by the potential effects of family history of breast cancer (mother or sister); health beliefs regarding mammography screening and breast cancer; and personal resources (social support, economic adequacy, and insurance coverage) within the context of MS-related functional limitations and contextual factors (age and education).

The underlying assumptions for the Breast Cancer Screening Model for WWCDC, consistent with the Explanatory Model of Health Promotion and Quality of Life in Chronic Disabling Conditions (Stuifbergen et al., 2000) include the following: (1) individuals have the ability to assess their own competencies through self-awareness; (2) individuals seek to regulate their own behavior; (3) individuals interact with the environment over time; and (4) individuals value positive growth that is individualized.

Contextual Factors

In this study, the contextual factors include the following: MS-related functional limitations (severity of limitations) and demographic characteristics (age and education). Severity of MS related functional limitations is the primary contextual factor that is presumed to be negatively associated with the likelihood of regular mammography screening.

Health Beliefs/Mammography

Little is known about how beliefs about perceived benefits, barriers, of mammography screening and susceptibility to breast cancer contribute to annual mammography use for WWCDC. From the conceptual model, health beliefs related to mammography screening may influence mammography use. Perceived benefits of mammography use and perceived susceptibility to breast cancer may be positively

correlated with annual mammography use, while perceived barriers to mammography use may be negatively correlated with annual mammography use.

Personal Resources

Personal resources are extrinsic factors (including perceptions) that have a positive direct or indirect influence on health-promoting behaviors, functional limitations, disability, and quality of life (Stuifbergen et al., 2000). Social support perceived economic adequacy, and insurance status are the resources addressed in Figure 1. A variety of conceptualizations of social support are present in the vast body of research literature. Social support, a function of relationships has four categories: emotional, instrumental, informational, and appraisal support (Heaney & Israel, 2008). Social support is a personal resource that has been linked to physical and psychological health and health behavior through "stress-buffering" (Heaney & Israel, 2008). Although the influence of social support on mammography use has been shown to be a predictor of mammography use for women in the general population, little is known about the influence of social support as a predictor for mammography use for WWCDC (Scheuler et al., 2008). For this reason, social support, as a personal resource was included to examine its influence on mammography use in WWCDC in this study. Prior research of both women with and without disabilities indicate that financial resources (income) and insurance coverage are important positive predictors of mammography screening use (Chevarley et al., 2006; Schueler et al., 2008); hence, economic adequacy and insurance coverage were included as personal resources for this study.

Mammography Screening

Mammography screening is considered a health-promoting behavior as it has the potential to increase overall wellness and maximizes health potential through early

detection of breast cancer (Pender et al., 2006). The ACS (2012) recommends that women 40 or over receive a screening mammogram annually. Although there are differing guidelines for the frequency and age of initiation for screening mammography, the ACS (2012) guidelines were used for this study, as these are the guidelines currently used by most clinicians.

Summary

The Breast Cancer Screening Model for WWCDC used to guide this study is a synthesis of the HBM (Rosenstock et al., 1988) and the Explanatory Model of Health Promotion and Quality of Life in Chronic Disabling Conditions (Stuifbergen et al., 2000). The factors in this model are logically connected. The HBM has been used extensively to predict mammography use in diverse populations (Champion & Skinner, 2003; Pasick & Burke, 2008; Soskolne, Marie, & Manor, 2007; Yarbrough & Braden, 2001). The Explanatory Model of Health Promotion and Quality of Life in Chronic Disabling Conditions has been used to explain how several factors including severity of MS related functional limitations and perceived personal resources influence health promoting behavior and quality of life in persons with MS. By incorporating concepts from both of these models, The Breast Cancer Screening Model for WWCDC should support better prediction of mammography use within the context of having a chronic disabling condition.

DEFINITION OF TERMS

Severity of MS-Related Functional Limitations

Conceptual definition: Restrictions in the ability of an individual to perform usual physical and mental activities and roles (Verbrugge & Jette, 1994).

Operational definition: Severity of MS-related functional limitations was determined by the total score on the participant's response to the Incapacity Status Scale in Year 13 (Kurtzke, 1981).

Age

Conceptual definition: The number of years from birth to the present.

Operational definition: Age at Year 13 was determined by adding 10 years to the response to the question, "What is your age?" from the Year 3 Background Information Questionnaire.

Education

Conceptual definition: The highest level of education completed.

Operational definition: The participant's response to the number of years of school completed on the Background Information Questionnaire from Year 7.

Family History of Breast Cancer (Mother, Sister)

Conceptual definition: The incidence of a breast cancer diagnosis of a relative that is a sister or mother.

Operational definition: The family history of breast cancer (immediate) was determined by the response to the question, "Has anyone in your immediate family (mother, sister) ever had breast cancer?" on the Year 14 questionnaire.

Health Beliefs/Mammography

Health beliefs are convictions held by individuals surrounding their health that may influence health behavior. Health behavior is "a function of the subjective value of an outcome and of the subjective probability, or expectation that a particular action will achieve that outcome." (Glanz, Rimer, & Viswanath, 2008 p. 46). Beliefs related to

mammography use and breast cancer may influence screening behavior. In this study, beliefs about the perceived susceptibility to breast cancer, perceived benefits, and perceived barriers to mammography screening may influence mammography use.

Perceived Barriers/Mammography

Conceptual definition: An individual's beliefs about the costs or risks (tangible or psychological) associated with getting a screening mammogram.

Operational definition: Perceived barriers to mammography screening were determined by the total response score on the Barriers to Mammography subscale from the Breast Cancer Screening Belief Scales for Women with Disabilities (BCSBSWD) on the Year 13 questionnaire.

Perceived Benefits/Mammography

Conceptual definition: An individual's beliefs about the efficacy of mammography screening.

Operational definition: Perceived Benefits to mammography screening were determined by the total response score on the Benefits to Mammography subscale from the BCSBSWD on the Year 13 questionnaire.

Perceived Susceptibility to Breast Cancer

Conceptual definition: An individual's beliefs about the likelihood of developing breast cancer.

Operational definition: Perceived susceptibility was determined by the total response score on the Perceived Susceptibility subscale of the BCSBSWD on the Year 13 questionnaire.

Personal Resources

Resources are factors that have a positive influence on a health promoting behavior. For this study, resources are comprised of social support and perceived economic adequacy.

Social Support

Conceptual definition: "Aid and assistance exchanged through social relationships and interpersonal transactions." (Heaney & Israel, p. 191).

Operational definition: Social support was determined by the total response score on the Personal Resource Questionnaire (PRQ) (Weinert & Brandt, 1987) on the Year 13 questionnaire.

Economic Adequacy

Conceptual definition: The perception of whether one has sufficient economic means to cover everyday expenses.

Operational definition: Economic adequacy was determined by the average item score on the Economic Adequacy Instrument (Lobo, 1995) on the Year 13 questionnaire.

Insurance Coverage

Conceptual definition: The type of health coverage.

Operational definition: Insurance status is determined by the response (check list) to the question, "What kind of insurance coverage do you have?" on the Year 14 questionnaire.

Mammography Screening

Conceptual definition: A procedure using X-ray of the breast tissue to detect breast cancer.

Operational definition: Mammography screening was determined by the a single question, "How often do you usually get a mammogram?" on the Year 14 questionnaire. Response options included: "Every year," "Every 2 years," and "Less frequently than every 2 years."

ASSUMPTIONS

Based on the extant research and the conceptual framework, the assumptions for this study include the following:

1. The study participants responded to the survey questions as honestly and as accurately as possible.
2. Health beliefs precede health behavior.
3. Individuals have a free will and will be more likely to participate in a health behavior under supportive conditions.
4. Individuals may be more likely to participate in a health behavior if they are motivated to achieve well-being.
5. The key factors predicting mammography use are included in the conceptual model.

LIMITATIONS

The possible limitations of this study include the following:

1. The findings may not be generalizable to the overall population of women with MS, since this study employs a convenience sample of women who were

participating in an on-going longitudinal study on health promotion for person with MS.

2. Self-assessments of functional limitations are subjective but they reflect objective performance measures of functional limitations.
3. Self-report of mammography use may not be an accurate measure of regular mammography use.
4. Because this study is partly a secondary analysis, there was limited ability to alter some of the predictor variables or the sampling technique.

SUMMARY

This chapter discussed the background and significance surrounding the disparity in screening mammography use between women with and without chronic disabling conditions. The primary purpose of this study was to identify the influence of several factors on the likelihood of annual mammography use in a sample of women with MS. Specifically, the study examined the influence of severity of MS-related functional limitations, demographic characteristics (age and education), family history of breast cancer, health beliefs related to mammography screening (perceived benefits, barriers, and susceptibility to breast cancer), and personal resources (social support, economic adequacy, and insurance status) on the likelihood of annual mammography screening use. The Breast Cancer Screening Model for WWCDC, synthesized from the HBM (Rosenstock et al., 1988) and the Explanatory Model of Health Promotion and Quality of Life in Chronic Disabling Conditions (Stuifbergen et al., 2000) was used as the conceptual framework for this study. This chapter also provided the conceptual and operational definitions of the concepts examined in this study. Findings from this study

may provide valuable information about predictors of mammography use, which in turn, may inform strategies to improve mammography use in WWCDC.

Chapter 2: Review of the Literature

This chapter discusses the extant literature related to the constructs examined in this study. Specifically, this chapter will begin with a discussion on literature regarding screening mammography use. Next, the impact that functional limitations and disability have on the use of screening mammography use is discussed. This discussion is followed by a review of the research on the impact of certain demographic factors (age and education) on annual screening mammography use. Lastly, literature regarding the influence of personal resources (social support economic adequacy, and insurance coverage), beliefs about the perceived relative benefits over barriers of mammography screening, and perceived susceptibility of developing breast cancer on screening mammography will also be outlined.

MAMMOGRAPHY SCREENING

Mammography screening is an effective non-invasive procedure that has been shown to detect 80–90% of breast cancers and reduce the overall breast cancer mortality rate through early detection (ACS, 2009). If detected when localized (non-metastasized), breast cancer has a 99% five-year survival rate (ACS, 2012; Nelson et al., 2009). Mammography screening in conjunction with CBE and to some extent BSE, continue to be recommended for women to reduce the overall breast cancer mortality rate (ACS, 2012; USPSTF, 2009).

A recent meta-analysis for the USPSTF of eight randomized clinical trials showed a 15% and a 14% reduction in breast cancer mortality for women ages 39–49 and women ages 50–59, respectively (Nelson et al., 2009). A 32% reduction in breast cancer mortality for women 60–69 years of age has also been reported by the USPSTF (2009).

The meta-analytic study reported no available information for older women (>70 years); however, one statistical model estimated that screening mammography could account for a 30–35% reduction in breast cancer mortality and an increase in life-years of 18–22% for women 74–79 years of age (Nelson et al., 2009).

The guidelines for breast cancer screening, including screening mammography, have been a source of controversy recently because of inconsistency in the recommendations provided by the two leading cancer organizations, the ACS and the USPSTF. The ACS recommends that women (with an average risk for breast cancer) receive an annual screening mammogram and clinical breast exam, beginning at age 40 (ACS, 2012). The ACS does not place a maximum age at which to discontinue screening. Rather, it recommends that the decision to undergo screening be made on an individual basis and should take into account the overall benefits over risk of screening, as well as the woman's health status and life expectancy. In addition, ACS stresses the importance of *regular* screening mammography (ACS, 2011). The ACS bases the interval for mammography on "the duration of time a breast cancer is detectable by mammography before symptoms develop." (ACS Breast Cancer Facts & Figures 2011–2012, p. 17). Larger tumor size and advanced stage breast cancer is associated with a longer time interval between screenings (Taplin et al., 2004). Furthermore, more surgical and post-surgical treatment options are available when breast cancer is detected at early stages of the disease (ACS, 2013).

Until recently, the USPSTF guidelines for the recommended beginning age and frequency for mammography screening were fairly consistent with those of the ACS (2012) (USPSTF, 2009). However, in November 2009, the USPSTF changed it's 2002 recommendation that women 40 years and older be screened every 1–2 years to the recommendation that women 50–74 years receive mammograms biennially stopping at

age 74 (USPSTF, 2009). Under the new USPSTF guidelines, for women under 50 years of age, the decision on whether to get a mammogram is on an individual basis with consideration to the benefits and harms of mammography. For women over 74 years of age, the USPSTF reports that there is insufficient information from the meta-analysis study regarding the added benefits/harms of screening (USPSTF, 2009).

The USPSTF (2009) based its decision to change the minimum age recommendation to 50 years of age on the claim that the net benefit (over harms of getting a mammogram) is small for women 40–49 years of age. The harms claimed by the USPSTF include the inconveniences of false-positive readings, psychological distress, radiation exposure risk, pain, unnecessary biopsies, and overdiagnosis of breast cancer (diagnosis of early breast cancer that may never become clinically significant) (USPSTF, 2009). Interestingly, although women 40–49 years old have higher false-positive rates than women over 50 years old, they are less likely to have biopsies than older women.

In response to the USPSTF study (Nelson et al., 2009), Hendrick and Helvie (2011) examined the number of years a woman would have to engage in annual mammography screening to encounter a "harm" as described by the USPSTF (2009). Using the same data source as the USPSTF study, the researchers estimated that women 40–49 years old, receiving annual mammograms, would have one false-positive mammogram result every ten years, get recalled (call back for further screening) once every 12 years, undergo a false-positive biopsy once every 49 years and have a missed breast cancer diagnosis once every 1,000 years. Researchers also reported that the mean mortality (from breast cancer) reduction from annual screening for women 40–84 years of age is 71% higher than from biennial mammography screening. This study provides support for the ACS (2013) recommendations of annual mammography screening for

women less than 50 years of age with an average risk of breast cancer. Armstrong, Moye, Williams, Berlin, and Reynolds (2007) in a review of 117 studies, reported that women ages 40–49 had higher rates of false-positive results (20–56%) after 10 mammograms. These researchers also indicated that the higher rates of false-positive results did not produce deleterious psychological effects, which dilutes the USPSTF argument that false-positive results may result in undue psychological harm.

In the general population, the mammography rate for women 40 years old or older was 29% in 1987 and reached the *Healthy People 2010* objectives of 70% in 2000 (U. S. Department of Health and Human Services [USDHHS], 2011); however, it dipped in 2005 and then was stable from 2005-2008 (Breen, Gentleman, & Schiller, 2011). According to the 2010 NHIS data, the overall biennial mammography screening rate for women over 40 years old was 72.4%, which is below the *Healthy People 2020* target of 81.1% (USDHHS, 2012). Not surprisingly, the annual mammography screening rate was lower, ranging from 46.8% (40–49 year olds) to 56.1% (50–64 year olds) (USDHHS, 2012). Interestingly, a recent study showed that despite the change in recommendations made by the USPSTF, the annual mammography rate has remained unchanged (Pace et al., 2013).

According to the CDC, the overall biennial mammography rate for women (40 years and older) with self-reported disabilities was 72.3%, which was 5.5 percentage points lower than the screening rate for women without disabilities (CDC, n.d.). A study using the 2008 BRFSS data showed the biennial screening rate for WWCDC ranged from 64.6% (40–49 year olds) to 80.4% (65–74 year olds) (Courtney-Long et al., 2011). Increasing the mammography rate among WWCDC is particularly significant since WWCDC have been shown to have a higher breast cancer mortality rate than their non-disabled counterparts (McCarthy et al., 2006; McCarthy et al., 2007).

In summary, despite the recent controversy surrounding the age of initiation and frequency of screening mammography, research suggests that regular mammography screening reduces the mortality rate by detecting breast cancers at early, treatable stages. For this dissertation study, the ACS guidelines calling for regular annual mammography screening will be used, since these guidelines have been used consistently in clinical settings.

FUNCTIONAL LIMITATIONS AND SCREENING MAMMOGRAPHY

The relatively scarce research conducted on breast cancer screening and WWCDC has yielded mixed results. There is substantial research that suggests that WWCDC are less likely to get screening mammograms than their non-disabled counterparts depending on the severity and type of limitation(s) (Armour, Thierry, & Wolf, 2009; Chan et al., 1999; Chevarley et al., 2006; Courtney-Long et al., 2011; Iezzoni et al., 2000; Iezzoni et al., 2001; Reichard, Stolze, & Fox, 2011; Schootman & Jeffe, 2003; Wei et al., 2006). The following discussion will include mammography screening behavior by WWCDC as compared to women without disabilities and the influence that severity and type of functional limitation(s) have on screening use among WWCDC.

Several population-based studies using large national survey data provide evidence that WWCDC are less likely to participate in mammography screening than women without disabilities (Courtney-Long et al., 2011; Iezzoni et al., 2000; Iezzoni et al., 2001; Reichard et al., 2011). For example, in an early study using data from the 1994 National Health Interview Survey with the disability supplements (NHIS-D), Iezzoni and colleagues (2000) reported that only 45.3% of women over 50 years of age with self-reported mobility impairment received mammograms, compared to 63.5% of women with no reported disabilities. Similarly, in a later study using data from the 2008

Behavioral Risk Factor Surveillance System (BRFSS), Courtney-Long and colleagues (2011) reported lower mammography use for women with disabilities (72.2% and 78.1% for women over 40 years old and 50–74 years old, respectively) compared to women without a disability (77.8% and 82.6% for women over 40 years old and 50–74 years old, respectively). These significant differences in the likelihood of screening for WWCDC compared to women without disabilities persisted even after controlling for sociodemographic factors inclusive of insurance status, education, income, cost-related access to care, marital status, race, and region of residence (e.g., Northeast and Midwest). Therefore, these findings suggest that functional limitations have an independent effect on mammography use in women with disabilities. Likewise, Reichard and colleagues (2011), in a retrospective study using population-based data from the Medical Expenditure Panel Survey (MEPS), found that women over 40 years old with cognitive or physical limitations were less likely to have received a mammogram in the last two years than women with no disability (AOR 1.69; CI 1.30–2.20 for cognitive limitations; AOR 1.22; CI 1.02–1.45 for physical limitations).

The level or severity of self-reported functional limitations has also been found to be directly associated with mammography use (Chan et al., 1999; Chevarley et al., 2006; Iezzoni et al., 2000; Iezzoni et al., 2001; Thierry, 2000). In an early study using Medicare participants (N = 8,530), Chan et al. (1999) found a 57% reduction in mammography use for women with self reported limitations in five or six activities of daily living (ADL) compared with women with no limitations. The odds ratios of getting a mammogram were 0.78 for women with no limitations, 0.65 for women with three to four ADL limitations, and 0.44 for women with five to six ADL limitations. Likewise, other researchers reported that women 65 or older, with three or more physical limitations were less likely to engage in mammography screening than younger women (<65) with less

than three functional limitations (Chevarley et al., 2006). Chevarley and colleagues (2006) in their population-based study (N = 77,762), indicate that although having functional limitations negatively influences mammography use, this was only true for women with three or more functional limitations. There was no statistically significant difference in mammography use in the past year between women with one to two functional limitations compared to those with no self-reported functional limitations. Likewise, Iezzoni and colleagues (2001) found women who reported having major long-term lower extremity mobility impairment were less likely to engage in mammography screening than those who reported having only some mobility difficulties.

The type of disability or functional limitation experienced by women also contributes to mammography use (Ahmed, Smith, Haber, & Belcon, 2009; Iezzoni et al., 2001). For example, Iezzoni and colleagues (2001) found that compared to women with no reported disabilities, mammography rates were comparable for women with hearing impairment; lowest for women with serious mental health issues and women with major lower extremity mobility impairment. Ahmed and colleagues (2009) found that women with severe physical limitations (inability to walk a quarter of a mile, climb 10 steps without resting, and standing for two hours) were more likely to receive mammograms than their nondisabled counterparts. On the other hand, they found that women with moderate limitations in the ability to engage in social activities (e.g., visiting friends, participating in meetings, and attending parties) were less likely to engage in mammography screening (OR, 0.62; 95% CI, 0.48–0.81) than women without disabilities. Ahmed et al. (2009) suggest that women with physical limitations are more likely to receive mammograms due to having more exposure to health care providers, who may provide mammogram referrals, than women with other types of functional limitations.

Among the various types of disabilities, women with cognitive disabilities have lower rates of mammography screening than women with other functional limitations or those women without limitations (Legg, Clement, & White, 2004; Reichard et al., 2011). Legg and colleagues (2004) used the 1998 NHIS data to examine the influence of self-reported cognitive limitations (difficulty remembering or confusion) and other functional limitations (activities of daily living [ADL], instrumental activities of daily living [IADL] on annual mammography use). Women with cognitive limitations, but not women with ADL or IADL limitations, were significantly less likely to engage in screening compared with the general population (AOR 0.66, CI 0.45–0.97). Similarly, Reichard and colleagues recently found that women with cognitive limitations had the lowest on-time mammography participation when compared with women with physical disabilities and women with no disabilities. Women with cognitive limitations were more than one and a half times less likely to engage in on-time mammography screening than women without limitations (AOR 1.22, CI 1.02–1.45).

Although much of the limited research suggests that women with disabilities are less likely to engage in mammography screening than women in the general population, not all studies have found differences in mammography use by disability status (Clark et al., 2009; Diab & Johnston, 2004; Liu & Clark, 2008; Nosek & Howland, 1997). In an early study, using a convenience sample (N = 479) Nosek and Howland found that although there was a significant difference in the frequency of pelvic exams, this difference did not persist for mammography screening when accounting for demographic variables. However, this study employed a convenience sample comprised of highly educated, primarily Non-Hispanic White women, which may have contributed to the lack of statistical significance. Similarly, in two more recent studies using convenience samples of unmarried women participating in the Cancer Screening Project for Women (*n*

= 630; *n* = 186, respectively), researchers did not find any significant differences in routine (on-schedule) mammography screening due to disability status (Clark et al., 2009; Liu & Clark, 2008). However, Clark and colleagues found a significant interaction between disability status and positive experiences for repeat mammography. Interestingly, women without disabilities had mammography rates of 59%–86% whereas, WWCDC had mammography rates of only 37%–60% depending on the number of positive experiences reported.

In summary, many of the research studies on mammography screening behavior among women with disabilities suggest that women with varying levels of functional limitations underutilize mammography screening compared with their non-disabled counterparts (Courtney-Long et al., 2011; Iezzoni et al., 2000; Iezzoni et al., 2001; Reichard et al., 2011). The level of severity and type of functional limitations are predictive of mammography screening use (Ahmed et al., 2009; Chan et al., 1999; Chevarley et al., 2006; Iezzoni et al., 2000; Iezzoni et al., 2001; Legg et al., 2004; Thierry, 2000). Some studies have found that disability status is not predictive of mammography screening use (Clark et al., 2009; Liu & Clark, 2008; Nosek & Howland, 1997). These studies, however, report that women are less likely to be on schedule for routine mammography screening as a result of the difficulty in performing the procedure and their overall negative experience (Clark et al. 2009; Liu & Clark, 2008). Sampling bias in these studies may partly contribute to the findings, which suggest no significant difference in mammography use between women with and without self-reported functional limitations.

DEMOGRAPHIC FACTORS AND MAMMOGRAPHY SCREENING

Age

Age has been found to be a consistent and significant predictor of mammography screening although the direction has varied (Bluestein & Weiss, 1998; Courtney-Long et al., 2011; Gierisch, Earp, Brewer, & Rimer, 2010; Liu & Clark, 2008; Lopez, Khoury, Dailey, Hall, & Chisholm, 2009; Ostbye, Greenberg, Taylor, & Lee, 2003). Data from the NHIS indicate that in 2010, women 50–64 years old had the highest annual mammography rate (56.1%) followed by women 65 and older (49.2%) and lastly, women 40–49 years old (46.8%) (ACS, 2012). In a longitudinal study examining repeat screening, using PRISM (Personally Relevant Information about Screening Mammography) data (N = 1,493), women who were 40-49 years old and who rated their health as "poor" had a lower mammography adherence rate over three years than those women who were 50 years or older (Gierisch et al., 2010). Likewise, in a recent study using data from the BRFSS, Courtney-Long et al. (2011) found that among women with disabilities, younger women (40–49 years old) had the lowest mammography rate (64.6%) followed by women 50–64 years old (71.1%). In contrast to the findings from the 2010 NHIS (CDC, 2010), Courtney and colleagues (2011) reported that older women with disabilities (65–74 years old) had a higher self-reported mammography rate of 80.4%.

Conversely, other research shows the inverse association between age and mammography use among WWCDC and those in the general population (Bluestein & Weiss, 1998; Liu & Clark, 2008; Lopez et al., 2009; Ostbye et al., 2003). For women in the general population, there may be as much as a 30–40% decrease in mammography use after 70 years old (Ostbye et al., 2003). In a study (N = 987) comparing women 40 years old and older, who are "current," "overdue" or "never" screeners, Lopez and

colleagues (2009) found that women who were 70 years of age or older were significantly more likely to be overdue for their annual mammogram compared to women 50–59 years of age (AOR 0.43 95% CI 0.2–0.9). In a study examining age (>75 years old) and functional status as predictors of mammography use (N = 2,352), Bluestein and Weiss (1998) reported that women over 85 years old were less than half as likely to get mammograms as women 75–79 years old (AOR 0.41, 95% CI 0.27–0.64) (Bluestein & Weiss, 1998).

In summary, much of the literature generally suggests that the relationship between age and mammography use is curvilinear in nature, with women at both ends of the age spectrum (40–49 and >65 years old) having lower mammography rates than women ages 50–64. The lower mammography rate for younger women may reflect the recent changes in the recommended age to start mammography screening (50 years old) (USPSTF, 2009). Older women, especially those 70 years and older may be generally less inclined to get screened because they may lack knowledge of the benefits of mammography (Scheuler et al., 2008). In addition, they may be less likely to receive a physician referral for a mammogram than their younger counterparts (Grady, Lemkau, McVay, & Reisine, 1992). Finally, they may have a reduced perceived risk for developing breast cancer, especially if they have been asymptomatic of breast disease (Burack, George, Gurney, 2000; Nosek & Howland, 1997; Scheuler et al., 2008).

Education

Substantial research in the general population suggests that level of education is associated with mammography use (Miller & Champion, 1993; Phillips, Kerlikowske, Baker, Chang, & Brown, 1998; Scheuler et al., 2008; Schootman & Jeffe, 2003). A meta-analysis of 221 studies from 1988 to 2007 of the general population suggests that low

education level (less than a high school level) is consistently related to underutilization of mammography (Summary AOR 0.78) (Scheuler et al., 2008). However, education as a predictor of mammography use was found to be less powerful in later studies than in earlier studies, suggesting a relative decrease in the importance of education level over time.

Interestingly, a more recent study using 2000 NHIS data found that education level positively predicts mammography use when comparing women with a high school diploma/some college, college, and master's degree to women without high school diplomas. However, women with professional/doctoral degrees were equally as likely to get mammograms as non-high school graduates (Ahmed et al., 2009). On the other hand, women with master's degrees were almost twice as likely (AOR 1.95, 95% CI 1.42–2.68) and women with college degrees were more than one and a half times (AOR 1.62, 95% CI 1.33–1.98) as likely to get mammograms than women without high school diplomas.

In a study examining repeat mammography screening in women with and without disabilities, Clark and colleagues (2009) found no difference in repeat mammography adherence for WWCDC by education level. Among WWCDC, 51.8% of women with a high school level of education or less schooling and 59.5% of women with a college education or more schooling were on-schedule for their mammograms. These percentages were significantly lower than those of women without disabilities (78.8% with a college degree or more and 56.3% of women with less than college degrees).

Overall, research suggests that education level influences mammography use with lower education levels negatively associated with mammography use. Lower education (and thus lower literacy) has been associated with negative perceptions of the mammogram process and inadequate knowledge regarding mammography (Peek & Han, 2004). Education as a predictor of mammography use is particularly salient among

women with disabilities, considering that women with disabilities, especially those with more severe limitations, are significantly more likely to attain only a high school level of education or less (Chevarley et al., 2006).

FAMILY HISTORY

Substantial literature suggests that the presence of a family history of breast cancer is associated with mammography adherence in the general population (Haber, Ahmed & Pekovic, 2012; Murabito et al., 2001; Scheuler et al., 2008; Townsend, Steele, Richardson, & Stewart, 2012). Using data from the Framingham longitudinal study (N = 683), Murabito and colleagues (2001) reported that women with a positive family history of breast cancer were more than three times (AOR 3.2, 95% CI (1.4–7.7) likely to have repeat mammograms than women with no family history of breast cancer. Interestingly, only 33% of the women with a positive family history of breast cancer gave family history as the reason for getting screened which may reflect the influence of other factors in the decision-making process regarding mammography use. Similarly, a more recent meta-analysis by Scheuler and colleagues (2008) showed that family history of breast cancer, especially in younger women, was a positive predictor of mammography use (AOR 1.45, 95% CI 1.28–1.64). A recent study using the 2005 NHIS data (N = 6,706) examined the relationships between, family history of breast cancer, family history of cancer other than breast cancer, risk perception (of developing breast cancer) and repeat mammography use in a six years (Haber, Ahmed, & Pekovic, 2012). Women with a family history of breast cancer had the highest repeat annual mammography rates (47–48%, six mammograms in six years), followed by women with a family history of another cancer (not breast) (40–41%), and women with no family history of cancer (37–38%). The type of relative was associated with the mean number of mammograms

received in the past six years. Women whose mothers only had a history of breast cancer, or mothers and sisters who had a history of breast cancer had an average of 0.5 more mammograms in the past six years ($p < 0.001$) compared to women with no family history of breast cancer. Women whose sister, daughter or first-degree male relative who had a breast cancer history had a lower average increase (0.45) ($p = 0.01$) in their mammography rate in six years. Not surprisingly, Haber and colleagues (2012) also reported a strong relationship between the risk perception of getting breast cancer and a family history of breast cancer or another cancer, which varied according to the type of relative (mother, sister, daughter and/or first degree male relative) with the family history.

The strong relationship between a family history of breast cancer and mammography adherence may have some negative implications if women base their decision to get mammograms solely on the presence of this family history. Having a positive family history of breast cancer has been shown to contribute to only 15–20% of all breast cancers (ACS, 2013). An overemphasis placed on the presence of a family history may reflect a lack of complete understanding of the impact of other risk factors related to breast cancer (e.g., obesity and age), which may actually deter women from getting screened. For WWCDC, avoiding overemphasis on the significance of family history for mammography decision-making is particularly salient since WWCDC are more likely to obese and older, which are known to be significant risk factors for developing breast cancer (ACS, 2012; Chevarley et al., 2006; Reichard et al., 2011).

HEALTH BELIEFS AND MAMMOGRAPHY

The next section will review the literature regarding the HBM variables used in this dissertation study: perceived susceptibility to breast cancer, perceived barriers and

benefits to mammography screening use. Since there are a lack of targeted studies specifically focused on women with disabilities and HBM variables, the following review will be comprised primarily of literature from the general population.

Perceived Susceptibility

Perceived susceptibility (risk), one's belief about the likelihood of developing an illness (e.g., breast cancer), has been studied extensively as a predictor of adherence to mammography screening in the general population (Calvocoressi et al., 2004; Champion, 1991; Champion & Menon, 1997; Champion et al., 2008; Champion & Scott, 1997; Champion & Skinner, 2003; Halabi et al., 2000; Katapodi et al., 2009; Katapodi et al., 2004; Stein, Fox, Murata & Morisky, 1992; Thomas, Fox, Leake, & Roetzheim, 1996). Two meta-analyses (Katapodi et al., 2004; McCaul, Branstetter, Schroeder, & Glasgow, 1996) and an earlier integrative review of the literature (Yarbrough & Braden, 2001) report a significant positive relationship between perceived susceptibility and mammography screening. In an early meta-analysis using 19 studies published between 1980–1994, McCaul and colleagues (1996) reported a small, but significant effect size ($g = 0.16$, $N = 11{,}678$) for the association between perceived risk and mammography use. Adding data (studies) from the McCaul et al. (1996) meta-analysis, Katapodi and colleagues (2004) conducted a meta-analysis on 32 studies ($N = 52{,}766$) and demonstrated that perceived risk is positively correlated with mammography screening. Although statistically significant, this overall average effect size was small ($g = 0.19$). A positive small correlation between perceived susceptibility or risk and mammography use was also described in an integrative review of 16 studies using HBM variables (Yarbrough & Braden, 2001). It is possible that the relatively low predictive value of

perceived susceptibility on mammography behavior may be due to the potential indirect influence of perceived susceptibility on behavior.

The influence of perceived susceptibility or risk related to mammography screening is inherently dependent on a woman's interpretation and accuracy of her risk of developing breast cancer (Katapodi et al., 2004; Katapodi et al., 2009). There is substantial evidence to suggest that women may not have an accurate perception about their risk for developing breast cancer (Katapodi et al., 2004). In general, women are likely to have optimistic bias; women perceive that they are less likely to be negatively impacted by negative life events including illness (breast cancer) (Weinstein & Nicolich, 1993). Recently, Katapodi and colleagues (2009) (N = 184) examined the relationship between perceived risk and objective risk (based on objective risk factors) for breast cancer related to mammography use. A noteworthy finding was that most women (89%) with higher objective risk for breast cancer underestimated their actual risk for breast cancer by reporting a risk lower than the average for women their same age. These researchers also report that although not statistically significant, there was a negative correlation between women who perceived low to average risk of developing breast cancer and mammography screening.

Several factors influence the perceived susceptibility/risk of developing breast cancer (Katapodi et al., 2004). Sociodemographic factors such as education level, age, and family history influence susceptibility/risk perception (Cronan et al., 2008; Haber et al., 2012; Katapodi et al., 2004; Katapodi et al., 2009; McQueen, Swank, Bastian, & Vernon, 2008). For example, education has been found to be a significant positive predictor of perceived susceptibility. Several studies have found that women whose education level is high school or less are more likely to have inaccurate risk perceptions either being unaware or overestimating their risk (Katapodi et al., 2004). In contrast,

women with at least a college education are more apt to perceive higher susceptibility (Katapodi et al., 2004; McQueen et al., 2008).

In addition to education level, age has been found to be a negative correlate of perceived susceptibility in women (McQueen et al., 2008; Katopodi et al., 2004). Grunfield, Ramirez, Hunter, and Richards (2002) reported that 25% of women believed they were "too old" to get breast cancer. Likewise, in a recent qualitative study of women with MS, one 80 year-old woman, despite being at higher risk due to a strong family history of cancer, reported she "probably wouldn't get it (breast cancer)" since she had "lived this long without it." (Todd & Stuifbergen, 2011, p. 54). A lower risk perception to breast cancer among older woman has serious implications as age is a risk factor for both disability and breast cancer.

Family history has a strong positive association with perceived susceptibility to breast cancer (Haber et al., 2012; Katapodi et al., 2004; Katapodi et al., 2009; McQueen et al., 2008). Haber and colleagues (2012), using population-based data reported that women with a positive breast cancer family history had higher risk perception levels (perception of the relative likelihood of developing breast cancer) (36–51% more likely) than women with no breast cancer family history (8–11% more likely). In addition, women who had a maternal family history of breast cancer had 32 times higher risk perception levels than women with no family history of breast cancer.

Perceived barriers and benefits to mammography

A substantial body of literature supports the association of perceived barriers and benefits to mammography screening in the general population (Champion et al., 2008; Champion et al., 2004; Lauver, Henriques, Settersten, & Bumann, 2003; Lee-Lin et al., 2008; Yarbrough & Braden, 2001). In general, studies have consistently found perceived

barriers to be a significant direct negative predictor of mammography screening (Champion, 1999; Champion & Menon, 1997; Champion & Scott, 1997; Champion & Skinner, 2003; Champion et al., 2004; Champion et al., 2008; Lee-Lin et al., 2008; Stein, Fox, Murata, & Morisky, 1992). In a study (N = 694) based on the Transtheoretical Model and the HBM, Champion and Skinner (2003) found that scores on perceived barriers and benefits to mammography scales predicted stage of mammography adoption (pre-contemplation to action). Specifically, women who scored highest on perceived barriers and lowest on perceived benefits to mammography screening fell into the earlier stages of mammography adoption (pre-contemplation or the contemplation stage). In contrast, women who reported few barriers and high perceived benefits to screening were in the action stage (adherent) of mammography adoption. Champion and colleagues (2008) reported similar findings in a study that examined the associations of fear and the HBM variables on stage of mammography adoption in a sample of 344 low-income African American women. The findings indicated that barriers and fear, together as well as independently, predicted mammography stage of adoption. With fear and barriers in a logistic regression, the authors estimated a 0.84 decrease in the odds of getting a mammogram for every five-unit increase in the perceived barriers score and a 1.19 increase for every five-unit increase in the fear score while adjusting for other factors. As expected, the mean benefit score was significantly higher for women in the action stage (already obtained mammogram) when compared to the score for women in the pre-contemplation stage (Champion et al., 2008).

In contrast to these studies, Lopez, Khoury, Dailey, Hall, & Chisholm (2009) in a population-based study (N = 987) comparing women who were "current," "overdue," or "never" screened found beliefs about the benefits but not barriers of mammography screening ("mammogram is the best way to find small lump") to be significantly

associated with pattern of screening. Fewer women who were overdue or never screened affirmed the benefits of mammography screening compared to women who were current on their screening. However, perceived barriers related to pain, embarrassment, time consumption, or radiation causing breast cancer were not significantly related to the screening pattern. Interestingly, women who maintained fatalistic views ("would rather not know") were more likely to be overdue or never screened than current screeners.

HEALTH BELIEFS ABOUT MAMMOGRAPHY FOR WOMEN WITH CHRONIC DISABLING CONDITIONS

There is scarce literature that specifically examines beliefs about mammography screening, specifically using the HBM constructs in WWCDC. In an early study (N = 843) examining adherence and barriers to regular breast and cervical screening, 23.5% of the women expressed that "their risk of getting breast cancer was very low." (Nosek and Howland, 1997, p. S-42). Similarly, older women (>65) with vision, hearing, learning, and multiple limitations have reported "not needing a mammogram" as a reason for not adhering to screening (Yankaskas et al., 2009). In this same study that examined reasons for not getting routine screening mammograms according to the type of disability, Yankaskas and colleagues (2009) reported that "lack of a breast problem" was the most frequently reported reason for not adhering to mammography screening. These findings reflect a lack of awareness, which may contribute to both a lack of perceived susceptibility to breast cancer and to a lack of perceived benefits of mammography.

With respect to perceived benefits to mammography screening, Clark and colleagues (2009) surveyed women with and without disabilities on the importance of getting a mammogram as compared to other medical procedures. Women with disabilities reported that mammography screening was "equally or more important than other medical issues," reflecting their positive perception of the benefits of screening. With

respect to perceived barriers, several studies have examined barriers experienced by WWCDC. However, these studies have not examined how health beliefs, using the HBM constructs influence mammography adherence in this population. The following section will describe the extant literature reviewing the barriers to mammography screening for WWCDC.

Barriers to Mammography Screening for Women with Chronic Disabling Conditions

Women with chronic disabling conditions face a myriad of obstacles specifically related to their disabling conditions. (Todd & Stuifbergen, 2012). These barriers include those related to an environment that fails to accommodate the needs of WWCDC. For example, several qualitative studies have reported that WWCDC experience difficulties with accessible, reliable public transportation (Barr, Giannotti, & Van Hoof, Mongroven, & Curry, 2008; Mele et al., 2005; Smeltzer, Sharts-Hopko, Ott, Zimmerman, & Duffin, 2007; Thierry, 2004; Todd & Stuifbergen, 2012). Public transportation designed for persons with disabilities often requires WWCDC to deal with the inconvenience of difficult transfers, long waiting periods, and inconsistent accessibility to services (Smeltzer et al., 2007). In a qualitative study, WWCDC reported having issues with qualifying for transportation services due to the low-income eligibility criteria (Mele et al., 2005). In addition, the women reported that insufficient hours of public transit service operations and the need for scheduling in advance (2–3 days ahead of time) contributed to their transportation difficulties (Mele et al., 2005). For women with MS, who report fatigue to be a major barrier to activities of daily living (Becker & Stuifbergen, 2004), these transportation obstacles can be especially burdensome. In rural areas, WWCDC consistently face greater public transportation challenges related to inconsistent coverage (Schootman & Fuortes, 1999).

Other environmental barriers to mammography screening for WWCDC include difficulty getting to and from the facility parking area, inaccessible medical buildings, waiting rooms and mammography equipment that does not accommodate women unable to stand for the procedure (Barr et al., 2008; Mele et al., 2005; Smeltzer et al., 2007; Todd & Stuifbergen, 2011; Yankaskas et al., 2009). Having equipment and tables that fail to accommodate women with functional limitations, especially those with mobility impairment, has contributed to the negative experience reported by WWCDC (Becker, Stuifbergen, & Tinkle, 1997; Liu & Clark, 2008; Nosek, & Howland 1997). In a study of women with physical limitations (N = 843), 34% of the women reported difficulty in positioning for mammography to be a barrier (Nosek & Howland, 1997). Difficulty in positioning due to unaccommodating exam tables and mammography equipment is responsible for the negative, sometimes embarrassing experiences noted by WWCDC (Becker et al., 1997; Liu & Clark, 2008; Nosek & Howland, 1997; Shabas & Weinreb, 2000; Todd & Stuifbergen, 2011; Yankaskas et al., 2009).

Environmental barriers to mammography screening may be disability-specific (Barr et al., 2008). Barr and colleagues (2008), in a qualitative study using disability-specific focus groups (physical, psychiatric, sensory, and cognitive limitations), found that women with physical and visual limitations more often reported barriers related to transportation, access to and within office buildings and inadequate mammography equipment than women with other types of impairment. Similarly, Yankaskas and colleagues (2009), in a descriptive study (N = 2,970) examining reasons for not maintaining a routine screening schedule, found that compared with women with single or no limitations, women with multiple limitations were significantly more likely to report transportation, facility access barriers and lack of MD referral as reasons for not returning for mammography screening.

Women with chronic disabling conditions often report having economic barriers to breast cancer screening (Barr et al., 2008; Chevarley et al., 2006). These barriers include the inability to pay for a mammogram as a result of inadequate insurance coverage (e.g., high co-payments) as well as transportation costs. Barr and colleagues (2008) found that with the exception of women with cognitive or developmental limitations, cost concerns related to co-payments and transportation emerged as barriers to mammography screening. The economic barrier to mammography screening is particularly salient for WWCDC since a large percentage (41%) of this population lives at or below the national poverty level and are more likely than their non-disabled counterparts to be unemployed (United States Census Bureau, 2006; Smith, 2008).

In addition to environmental and economic barriers, WWCDC often report barriers generated by health care providers. Women with chronic disabling conditions are often subjected to health care providers that communicate in a condescending, patronizing, and insensitive fashion reflective of a lack of knowledge regarding their needs (Barr et al., 2008; Becker et al., 1997; Nosek & Howland, 1997; Smeltzer et al., 2007; Todd & Stuifbergen, 2011). Furthermore, health care providers often engage in inappropriate stereotyping (Smeltzer et al., 2007). In a recent qualitative study with a sample of women with MS, one participant who needed help with undressing for her mammogram, reported that the technician was "rude" and commented that "she was not used to dressing a child" (Todd & Stuifbergen, 2011, p. 52). The quality of the experience has an impact on whether these women continue to have regularly scheduled mammograms (Liu & Clark, 2008; Clark et al., 2009). Liu and Clark (2008) found that unmarried women with disabilities were less likely to remain on-schedule for their mammograms compared to their non-disabled counterparts. Furthermore, compared to

women without limitations, a lower percentage of WWCDC reported having their privacy respected and having the procedure explained all or most of the time.

Several women with disabilities also indicate feeling as though their health care providers treat them in terms of their limitations, ignore their routine female preventive screening needs and fail to recommend mammograms (Smeltzer et al., 2007). One study of women with MS alluded to the notion that physicians may perceive women with MS to have a shortened life expectancy and therefore perceive that it is unnecessary to focus on preventive health screening (Cheng et al., 2001). Failing to recognize the need for screening is especially a problem if the health care provider is a specialist that may be more likely to focus only on disease management and not on the breast cancer screening needs of these women (Frey, Schiffrin, Bethel, Gonin, & Fan, 2003). Frey et al. (2003) found that women with MS who saw only a neurologist for their health care were almost two times less likely to have had mammograms in the last two years compared with those who saw both a non-neurologist and a neurologist for their care.

In addition to these barriers that may influence mammography behavior, women with chronic disabling conditions have discussed intrapersonal barriers as well. A qualitative study of 36 women with MS, found that some women reported not getting a mammogram because they feel they "already have enough to deal with," a concept referred to as *No Más,* and therefore they could not fathom having to deal with the implications of having another chronic illness, breast cancer. This feeling of *No Más* may in turn influence perceived susceptibility to breast cancer (Todd & Stuifbergen, 2011).

PERSONAL RESOURCES AND MAMMOGRAPHY SCREENING

The following section will provide an overview of the extant literature on the relationship between perceived resources or social support, social networks and

mammography screening. Since little research has been done specifically targeting WWCDC, the ensuing section will primarily focus on the research conducted in the general population including minority and low-income women.

House (1981), in his early work on social relations, defined actual or perceived social support as the functional dimension of social relationships and social networks, as the structural dimension of social relations. Social support refers to the type of support exchanged or received (emotional, instrumental, informational, and appraisal) while the concept of social network, refers to the composition (e.g., size, frequency of contacts, and demographic characteristics) in the ties between individuals. Social networks are viewed in terms of the dyadic characteristics such as the degree of reciprocity (given and received), the level of emotional strength, the degree of formality of the structure (institutional and familial), and the degree to which the relationship satisfies multiple purposes (Heaney & Israel, 2008). Social networks are the conduits for giving and receiving social support.

Extensive research, both observational and interventional, has examined the influence of multiple dimensions of social support (i.e., emotional, informational, instrumental, and appraisal) and social networks (i.e., size) on mammography behavior in the general population. (Allen, Stoddard, Mays, & Sorensen, 2001; Allen, Sorensen, Stoddard, Peterson, & Colditz, 1999; Allen, Stoddard, & Sorensen, 2008; Fite et al., 1996; Farmer, Reddick, D'Agostino, and Jackson, 2007; Jackson, 2006; Kang & Bloom, 1992; Kang, Bloom, & Romano, 1994; Messina et al., 2004). Although the findings have been mixed, some research using convenience samples as well as population-based samples, suggests that social support and/or social networks have a positive influence on mammography behavior (Jackson, 2006; Messina et al., 2004). Similarly, Jackson (2006) examined the influence of perceived social support received by family, friends and

significant others on health practices of 373 primarily White, highly educated men and women in a community setting on several health practices. Thirty-eight percent of the sample reported having at least one current medical condition persisting for more than six months. After controlling for age, education, and number of daily hassles, women who reported low social support from close relationships had significantly lower adherence to routine medical care than women who reported having more supportive close relationships.

In a large observational study using a national sample (N = 55,278) of postmenopausal women participating in the Women's Health Initiative, Messina and colleagues (2004) examined not only the influence of perceived functional social support, but also the influence that social burden has on breast cancer screening. The perceived social support dimensions that were examined included the following: emotional/informational support (access to someone who can exchange empathy encouragement, guidance, and advice) tangible support (availability of material assistance), affection support (availability of someone who makes you feel loved or wanted), and positive social interaction support (availability of someone with whom to participate in social activities), (Messina et al., 2004). The level of negative life events, social strain, and frequency of caregiving determined social burden. Social support and social burden were significantly and independently associated with repeat mammography. Lower perceived emotional/informational support and/or positive social interactions were associated with decreased repeat mammography use. Furthermore, frequent care giving was negatively associated with screening among low-income women with self-reported social burden. Interestingly, neither tangible support nor affection support was significantly related to repeat screening.

In contrast to the above studies, Kang and colleagues (1994), in a study of 670 African American women, found that although size of social networks was associated with mammography use, instrumental and emotional support was not associated with mammography use. Similar findings were reported in another study using a tri-racial/ethnic sample (N = 838) to identify the influence of social support (structural and functional) on adherence to breast cancer screening guidelines, including mammography screening (Katapodi, Facione, Miakowski, Dodd, & Waters, 2002). Although the authors of this study did not find social support to be associated with adherence to mammography screening, social support was positively related to clinical breast and breast self exam adherence.

A series of large intervention studies were conducted to evaluate the effectiveness of work-site-based educational interventions on regular mammography screening using different aspects of social networks and social support (Allen, Stoddard, Mays, & Sorensen, 2001; Allen, Sorensen, Stoddard, Peterson, & Colditz 1999; Allen, Stoddard, & Sorensen, 2008). In the early cross-sectional Woman to Woman Study (N = 1,045), Allen and colleagues (1999) found no significant difference between the network size and level of social support among women who adhered to screening compared with those who did not adhere to screening. Expanding on the earlier study, Allen and colleagues (2001) conducted a 16-month intervention study (N = 2,747), which incorporated group discussions, educational campaigns and peer health advisors (PHA) at the work-site with the goal of improving mammography screening use among employed women. Mammography screening rates did not improve significantly using social support strategies (PHA). In the latest study, Allen and colleagues (2008) extended this study by examining the influence of network size, social influence (norms), emotional, instrumental, and informational support on mammography screening in a prospective

longitudinal study of women (ages 40–51 and 52 years and older) in their worksites (N = 1,475). For women 40–51 years old, encouragement by family or friends predicted mammography use (OR 2.20, 95% CI 1.34–3.61) at follow-up. For women 52 years or older, the odds of getting a mammogram was 1.46 (95% CI 1.16–1.84) greater at follow-up if they reported that mammography was a normative behavior than if they did not report that mammography screening was normative. However, researchers also noted that there was no significant difference between the intervention group and the control group with regards to mammography screening.

There are several mechanisms explaining the positive influence of social networks and social support on mammography behavior. Social network size may directly influence the mammography decision-making process by increasing interactive exposure to individuals who may enhance knowledge about the benefits of mammography. Increased exposure through social networks may also extend coping options and provide solutions for potential stressors or barriers related to mammography. High emotional social support may improve overall psychological well-being, self-worth, and a sense of belonging, which may indirectly stimulate health responsibility and self-care behavior (Jackson, 2006).

In summary, although research findings have been inconsistent, substantial evidence suggests a positive association between social networks, social support, and mammography behavior. Furthermore, some research suggests emotional support may be especially influential for low-income women who have reported social burden. These findings are particularly salient for WWCDC since they are more likely to live well below poverty level. Women living with the potential stressors related to their chronic and disabling condition may be particularly vulnerable to social burden, which may be mediated by social support through close social ties and networks. This buffering effect

of social support may in turn, help WWCDC to focus on maximizing their wellness through mammography screening.

Insurance

The presence and type of insurance coverage have been consistently strong predictors of mammography use in both the general population and among women with disabilities (Ahmed et al., 2009; Courtney-Long et al., 2011; Scheuler et al., 2008; Wei et al., 2006). Population-based studies comparing the mammography use of women with and without disabilities indicate that uninsured women have the lowest mammography rate compared with those woman who have with public (Medicare and Medicaid) and private insurance (Ahmed et al., 2009; Courtney-Long et al., 2011; Reichard et al., 2011; Scheuler et al., 2008; Wei et al., 2006). Women in the general population are half as likely (AOR = 0.46, 95% CI [0.39, 0.57]) to get mammograms if they are uninsured (Scheuler et al., 2008) and women with public insurance are more likely to adhere to mammography screening than their counterparts with private insurance (Ahmed et al., 2009; Courtney-Long et al., 2011; Wei et al., 2006). Ahmed and colleagues (2009) reported that compared to uninsured women, women with public insurance were almost one and a half times more likely (AOR = 1.48, 95% CI [1.12,1.97]) and women with private insurance were two times more likely (AOR = 1.92, 95% CI [1.52, 2.42]) to get mammograms. Similarly, among WWCDC, Wei et al. (2006) found significant differences between the mammography rate by type of insurance (59% for those with no insurance, 73% for those with public insurance, and 81% for those with private insurance).

The prevailing evidence that insurance coverage strongly influences mammography use is particularly salient for WWCDC because these women are more

likely to have public insurance (Medicare, Medicaid, or both) than women without disabilities (Reichard et al., 2011). Interestingly, Chevarley and collegues (2006) in a study using NHIS-D data, reported that despite having insurance coverage, WWCDC cited a lack of insurance coverage as a primary reason for not getting screening mammograms, perhaps due to the cost burden of co-payments. Financial issues surrounding lack of insurance may be particularly salient for women with MS who have reported difficulty in qualifying for Social Security Disability Insurance (SSDI) (Iezzoni, Ngo, & Kinkel, 2007). Women with MS, like other women with chronic disabling conditions, are more likely to be unemployed due to disability compared with their non-disabled counterparts and therefore may not have attained the minimum employment history to qualify for SSDI. A relatively limited employment history may not be uncommon for women with MS since MS is most often diagnosed in relatively young women (20–40 years old) (NMSS, 2012). Furthermore, women with relapsing-remitting MS may be at risk for not qualifying for SSDI because of the intermittent nature of their condition (Iezzoni et al., 2007).

In summary, a large body of research supports a strong positive relationship between insurance status and mammography use among women with disabilities. Women with private insurance have higher mammography rates than women with public insurance or no insurance. Women with disabilities face multiple challenges related to insurance. They are more likely to have public insurance, which may translate into a higher cost burden related to co-payments. Women with MS, especially those with relapsing-remitting MS, may not have sufficient employment credits to qualify for SSDI, due to an insufficient employment history, and may face a cost-related downward financial spiral (Iezzoni et al., 2007).

SUMMARY

Extant research suggests that mammography screening is effective in reducing the overall breast cancer mortality rate amongst women (ACS, 2012). WWCDC are less likely to participate in mammography screening than their non-disabled counterparts (Courtney-Long et al., 2011). This prevailing screening disparity is significant as evidence suggests that WWCDC have at least the same or greater risk of developing breast cancer and have a higher mortality rate than women without disabilities (McCarthy et al., 2006). Research suggests that the degree and type of functional limitations may influence mammography use among WWCDC. Women who report higher levels of functional limitations, especially older (> 65 years old) WWCDC, are less likely to engage in screening than women with fewer or no limitations (Chevarley et al., 2006).

Regarding demographic factors, in general, researchers suggest a significant curvilinear relationship between age and mammography use. Women ages 50–64 report the highest rate of mammography screening. Higher levels of education and a positive family history of breast cancer have also generally been found to be positive predictors of mammography use (Scheuler et al., 2008).

The extant literature suggests that in the general population, health beliefs about perceived susceptibility (risk) to breast cancer, perceived barriers and benefits of mammography screening have been associated with mammography screening adherence. Among these belief factors, perceived barriers to mammography have the greatest ability to predict mammography use and perceived susceptibility to breast cancer has the least ability to predict mammography use (Yarbrough & Braden, 2001). There is relatively scarce research specifically targeted to health beliefs about mammography screening among WWCDC as a predictor of mammography behavior. The limited research suggests that WWCDC may have reduced perceived susceptibility to breast cancer

(Nosek & Howland, 1997) and they most commonly report "lack of a breast problem" as a reason for not adhering to screening (Yankaskas et al., 2009). Like women with no disabilities, WWCDC report cost as a barrier to mammography screening (Barr et al., 2008; Scheuler et al., 2008). Researchers also suggest that WWCDC face multiple barriers to mammography screening unique to WWCDC, including lack of transportation, inaccessible waiting rooms, mammography equipment that fails to accommodate women unable to stand, and health care providers who demonstrate a lack of knowledge and insensitivity to the needs of WWCDC (Becker et al., 1997; Mele & Pusch, 2005; Smeltzer et al., 2007; Todd & Stuifbergen, 2011).

Although there are some inconsistencies in the literature, in general, personal resources (social support, economic adequacy, and insurance) have been shown to be a positive influence on mammography screening in the general population (Jackson, 2006; Messina et al., 2004). Little is known about how personal resources influence the rate mammography screening for WWCDC. This dissertation will examine the potential "buffering" influence of personal resources on mammography behavior in WWCDC—a population particularly vulnerable to the burden of stress.

Chapter 3: Methods

This chapter describes the study design, study procedures including recruitment of the study sample, and procedures used for the protection of human subjects. In addition, procedures for data collection, instrumentation, and data analysis methods are also discussed.

DESIGN

This dissertation study uses a prospective descriptive correlational design. Data were collected over two years as part of a larger ongoing longitudinal descriptive study on health promotion for persons with MS, *Maximizing Health with Multiple Sclerosis*. The data used for analysis of the current dissertation study were collected in Time 13 and 14 of the parent longitudinal study. This dissertation study examined how contextual factors (self-reported MS-related functional limitations, age, and education), family history of breast cancer, health beliefs about mammography (perceived benefits, barriers, and susceptibility to breast cancer), and personal resources (social support, economic adequacy, and insurance coverage) influence mammography screening at Time 14.

STUDY PROCEDURES

Participant Recruitment

Participants were recruited initially for a cross-sectional study in 1996. A letter describing the study was sent to 2,722 individuals on the mailing list of two National MS Society chapters in Texas. Nine hundred thirty-six participants responded and requested surveys; 834 Time I surveys were returned (822 were useable) (Stuifbergen & Roberts, 1997). Of the participants who returned the Time I surveys, 774 were sent a brief follow-up survey in 1998. In 1999, following the continuation of funding, 749 eligible participants from the original study sample were mailed study information and consents

requesting their participation in the longitudinal study. A total of 621 usable survey questionnaires were returned (84.5% response rate). Participants who returned the 1999 questionnaire were contacted annually and received mailings with questionnaires once per year with six-month follow-up unless they requested to be dropped from the study, died, or were lost to follow-up. Each year, participants were provided with a $30 money order as financial incentive for participation in the study (Harrison, Stuifbergen, Adachi, & Becker, 2004). The response rates of those eligible to participate ranged from 83.1% to 89.7% through Time 14 and were 84.9% and 85.0% in Time 13 and 14, respectively.

Protection of Human Subjects

The University of Texas at Austin School of Nursing Departmental Review Committee and The University of Texas at Austin Institutional Review Board (IRB) reviewed and approved the MS longitudinal study. Participants in the longitudinal parent study were notified that the study was entirely voluntary and they had the option to discontinue participating in the study at any time. In addition, participants were informed that information provided by participants was confidential, would be stored in a secure, locked setting, and would only be used for research purposes only. The potential risks and benefits of participating in the study were disclosed to the participants. Participants were notified that risks were not expected to exceed those risks of not participating in the study.

The longitudinal parent study was reviewed annually and additions/changes made to the annual questionnaire were approved (including those for this dissertation study). The original study consent form as well as the letters of IRB approval for Time 13 and14 are in Appendix A.

INSTRUMENTATION

During each year of the longitudinal study (1999–present), participants have received a standard questionnaire battery with additional selected instruments or questions at each time point. The instruments to be used in the dissertation study included those administered as part of the annual questionnaire for the parent study as well as items and instruments related to breast cancer screening that were added specifically at Time 13 and 14. The following instruments were used in Time 13: Background Information Sheet; the Incapacity Status Scale (ISS) (Kurtzke, 1981); the Personal Resource Questionnaire (PRQ) (Weinert & Brandt, 1987); and the Economic Adequacy Scale (Lobo, 1995). In addition to the above instruments, three subscales from the Breast Cancer Screening Belief Scales for Women with Disabilities (BCSBSWD)(modified with permission from Champion's Health Belief Model Scales [CHBMS])(Champion, 1993) were used. These subscales include the Perceived Benefits to Mammography, Perceived Barriers to Mammography, and Susceptibility to Breast Cancer. The Background Information Sheet questions about family history of breast cancer, insurance coverage, and mammography from the Time 14 questionnaire were used for analysis in this dissertation study. The scores generated from the instruments in Time 13 were used to predict the outcome variable, mammography use in the past 12 months, obtained in the Time 14 questionnaire. Instruments used in this study are in Appendix B.

Background Information Sheet

The Background Information Sheet questions from Time 3, Time 7, and Time 14 provided the demographic data for this study. Demographic information such as marital status, education level (degree), type of MS, length of diagnosis, ethnicity, and employment status was collected in Time 14. Data regarding ethnicity were obtained

from participant responses provided at Time 3 and 7 of the ongoing longitudinal study. Data on number of years of education were collected from the Time 7 annual questionnaire. Data regarding age and time since MS diagnosis were collected in Time 3 of the ongoing longitudinal study.

Incapacity Status Scale

The Incapacity Status Scale (ISS), developed by Kurtzke (1981) was used in this study as a self-reported measure of level of functional limitations related to MS. The ISS was developed by the International Federation of Multiple Sclerosis Societies and has been validated in research on disability in persons with MS (Wingerchuk, Noseworthy, & Weishenker, 1997). For this study, the original scale designed for clinical assessment and recording of severity of physical functional limitations, was adapted from the structured interview format to a self-administered questionnaire format (Stuifbergen et al., 2000). The ISS, a 16-item scale, measures the degree of functional limitation in multiple domains, including ability to perform personal activities of daily living (i.e. bathing and dressing) as well as other measures related to bowel, bladder, vision, and sexual functioning. Each of the 16 items is rated on a 5-point rating scale, with "0" indicating no impairment in functioning and "4" indicating a complete inability to perform a given activity (e.g., dressing). The possible range of total scale scores is 0 to 64. The Cronbach's alpha from previous studies on this population range from 0.80 (Phillips & Stuifbergen, 2006) to 0.86 (Stuifbergen & Becker, 2001). The internal consistency reliability measure for the sample of the women used in this study was 0.87.

Personal Resource Questionnaire (PRQ)

The Personal Resource Questionnaire (PRQ) is a two-part instrument that measures the degree of self-reported perceived social support (Weinert & Brandt, 1987).

Only Part 2 of the PRQ was used for this study. Originally, the 25-item, Part 2 of the PRQ instrument was designed to measure five underlying dimensions of social support including (a) Worth (perception that one is valued), (b) Social Integration (perception that one is part of a group), (c) Intimacy, (d) Nurturance, and (e) Assistance (access to emotional, material and informational help) (Weinert & Brandt, 1987). Additional psychometric testing of the PRQ resulted in a change from the five-factor structure to a three-factor structure. The components extracted from factor analysis included, (a) Intimacy/Assistance, (b) Integration/Affirmation, and (c) Reciprocity.

The PRQ instrument uses a 7-point rating scale ranging from "1" "strongly disagree" to "7" "strongly agree." The range of scores is 25 to 175 with higher scores indicating higher perceived social support. Weinert and Brandt (1987) reported a Cronbach's alpha of 0.93. The Cronbach's alpha for the ongoing longitudinal study ranged from 0.92–0.94 for Years 3–13. The Cronbach's alpha for the sample used in this dissertation study was 0.95.

Economic Adequacy Scale

The Economic Adequacy Scale (Lobo, 1995) is a measure of the self-reported adequacy of financial resources. This 8 item instrument uses a 4-point rating scale ranging from "1" (not at all) to "4" (more than adequately) and the score for this scale is the mean item score of all answered items. The Economic Adequacy Scale is comprised of questions regarding economics of daily living including, "Does your family income allow you to meet your needs for daily living?," and "Does your family income allow you to meet health care needs?" The Cronbach's alpha measure of reliability ranged from 0.80 to 0.97 for the ongoing longitudinal MS study. The Cronbach's alpha measure of internal consistency for the sample in this dissertation study was 0.96.

Breast Cancer Screening Belief Scales for Women with Disabilities (BCSBSWD)

The BCSBSWD, a modification of the 1993 version of the Champion Health Belief Model Scales (CHBMS), was used to measure breast cancer screening beliefs in this study. The 1993 version of the CHBMS is a 53-item self-report instrument comprised of 7 subscales, namely, susceptibility to breast cancer (5 items); seriousness of breast cancer (7 items); benefits-mammogram (6 items); barriers-mammogram (5 items); benefits-BSE (6 items); barriers-BSE (6 items); confidence (11 items); and health motivation (7 items). The CHBMS uses a 5-point Likert scale for responses ranging from "strongly disagree" to "strongly agree." The CHBMS, a widely used instrument, has undergone several revisions, has been tested extensively in various cultures, translated into multiple languages, and has been validated as an effective tool for measuring beliefs about breast cancer, mammography, and BSE as well as adherence to screening (Champion & Scott, 1997; Lee, Kim, & Song, 2002; Parsa, Kandiah, Mohd, Hejar, & Nor, 2008; Secginli & Nahcivan, 2004; Zelviene & Bogusevicius, 2007). Permission to modify the CHBMS was obtained prior to the modification and development of the BCSBSWD.

An expert panel comprised of three persons reviewed the 1993 CHBMS items to assess the applicability of each item for women with chronic disabling conditions as well as item overlap. The expert panel was comprised of a doctorally prepared nurse researcher and two doctoral level faculty members, who were experts in disability research as well as cancer research. In addition, data collected as part of a qualitative study of barriers and facilitators of BCS in women with MS (Todd and Stuifbergen, 2011) were used to refine and modify the items in the CHBMS. The items from the CHBMS that had overlap were eliminated from the revised BCSBSWD. In addition, for the purpose of this study, the health motivation subscale from the CHBMS was not

included in the modification of the instrument. A total of 24 items from the 1993 CHBMS were removed for the BCSBSWD scale. Reducing the total number of items on the instrument would decrease potential test burden that WWCDC may experience (i.e., fatigue) in completing the instrument.

The BCSBSWD contains 29 items across six scales: barriers-mammogram (5 items); benefits-mammogram (7 items); benefits-BSE (4 items); barriers-BSE (7 items); self-efficacy-BSE (3 items); and susceptibility (2 items). The benefits-mammogram subscale assesses the degree to which a woman perceives that there are benefits to getting a mammogram. Conversely, the barriers-mammogram subscale assesses the degree to which a woman perceives a cost associated with getting a mammogram. The benefits-BSE and the barriers-BSE subscales, similar to the subscales for mammography, assess the perceived benefits and barriers (cost) associated with performing BSE. The self-efficacy-BSE subscale assesses the degree to which a woman feels confident in being able to perform BSE. The susceptibility subscale assesses perceived likelihood of developing breast cancer. Two items were added to the mammography-barriers subscale, which included, "Having a mammogram would be difficult because of lack of transportation" and "Having a mammogram would be difficult because it is hard to get positioned for the mammography machine." Although the entire instrument was administered in Year 13, only the subscales of benefits-mammogram, barriers-mammogram, and susceptibility to breast cancer subscales were used for analysis in this dissertation study.

Cronbach's alpha internal consistency measures for the three subscales used in this study were as follows: benefits-mammogram (five items), $\alpha = 0.83$, barriers-mammogram (seven items), $\alpha = 0.77$, and susceptibility to breast cancer (two items), $\alpha =$

0.80. Subscale total score ranges are as follows: 5–25 for the benefits-mammogram, 7–35 for the barriers-mammogram, and 3–15 for the susceptibility to breast cancer subscales.

To assess for construct validity of the scales, the 29 items from the six modified subscales were subjected to an exploratory factor analysis using principal component analysis to extract factors. Varimax rotation was used for orthogonal rotation of the factors with Eigen values set at >1. A factor loading criteria of 0.3 or above was used for item retention (Nunnally, 1978). Six components were extracted and the total variance explained for these factors was 64.8%. With the exception of one item from the susceptibility subscale "I don't think about getting breast cancer because I already have enough to deal with," all the items loaded in the subscales similar to the original CHBMS. The Cronbach's alpha of the Susceptibility Scale when including this item was 0.35. When the item was dropped from the scale, the Cronbach's alpha for the two-item susceptibility subscale was 0.80. Considering the low reliability, this item was not included in this analysis. This item may be a separate construct that may indicate the need for further instrument development related to this unique concept. However, it should be noted that limited variability in response does not indicate it is not an important issue among WWCDC.

Survey Questions

Survey questions were administered in Time 14 that included questions related to frequency of mammography use. Specifically, the question, "How often do you **usually** get a mammogram?" was asked in order to examine *regular* mammography use to be consistent with the ACS (2012) recommendations. The response options included, "every year, every 2 years, and less frequently than every 2 years," which were later dichotomized into "1" for "every year" and "0" for the other two responses. In addition,

Time 14 included survey questions regarding presence of immediate (mother, sister) family history of breast cancer ("yes" and "no") and type of insurance coverage (check list). Refer to Table 1 for a summary of the instruments used for this dissertation study.

Table 1

Summary of Study Instruments N = 274

Instrument	Variable(s)	Time (Year) Collected	Subscales	Number of Items	Reliability Cronbach's alpha(α)
Background Information Sheet	Age Education (Years)	3 7	NA	2	NA
BCBSWD Mammo. Subscales Suscept.	Beliefs related to: Benefits and Barriers/Mammo. Suscept. to Breast Cancer	13	3/6 used	15/29 used Benefits (5) Barriers (7) Suscept. (2)	Benefits α = 0.82 Barriers α = 0.78 Suscept. α = 0.80
Economic Adequacy Scale	Adequacy of Financial Resources	13	None	8	α = 0 .97
Incapacity Status Scale	Functional Limitations	13	None	16	α = 0.87
Personal Resource Questionnaire (PRQ85)	Social Support	13	None	25	α = 0.95
Survey Questions	Insurance Family HX /BR CA Usual Mammo. Use	14 14 14	NA	1 1 1	NA

Mammo. =Mammography; Suscept. = Susceptibility; Family HX/BR CA = Family History of Breast Cancer

SAMPLE

The convenience sample for this study included 274 women with multiple sclerosis (MS) who were participating in the on-going longitudinal study, *Maximizing Health with Multiple Sclerosis,* a study on health promotion and quality of life of persons with MS residing in southwestern U.S. The inclusion criteria for participants to qualify for this dissertation study were as follows: 1) women who met the original inclusion criteria with respect to a diagnosis of MS in the ongoing longitudinal study (a diagnosis of MS for one year by a physician, community-dwelling (Stuifbergen & Rogers, 1997); 2) women who had participated in both Time 13 and 14 of the ongoing longitudinal study; and 3) women who were at least 39 years or older in Time 13, (and therefore 40 years old in Time 14). Women were excluded from this dissertation study if they had a previous self-reported history of breast cancer, since having had breast cancer may impact mammography use. The participants needed to participate in both Time 13 and Time 14 since the outcome variable, frequency of mammograms was measured in Time 14. The minimum age requirement of 39 years old at Time 13 (and therefore 40 years old in Time 14) was used in order to be consistent with the recommended age of 40 years old to begin screening mammography (ACS, 2012).

DATA ANALYSIS

Analysis of the data in this study was performed using the Statistical Package for the Social Sciences (SPSS) Version 20.0 (IBM, 2011). The level of statistical significance for this study was set at $p < .05$. Descriptive statistics including frequency, means, and standard deviations were conducted to describe the study sample and the study variables. Binary logistic regression was used to analyze the data since the outcome variable mammography use is a dichotomous variable. Statistical analysis was conducted to test for any violations in the assumptions of binary logistic regression statistical

analysis. Pearson and Phi (for dichotomous variables) correlations were conducted to confirm associations between predictor variables and the outcome variable. To test for multicollinearity among predictor variables, the variance inflation factor (VIF) and tolerance tests were conducted and results indicated no concern for multicollinearity, (VIF < 10, tolerance test > .1(Field, 2012). The assumption for a linear relationship between the continuous predictor variables and the logit transform of the outcome variable (Tabachnik & Fidell, 2013) was met for all the continuous predictor variables with the exception of the susceptibility subscale. The perceived susceptibility subscale was dichotomized into high and low susceptibility to address this violation in assumptions. This method was selected instead of eliminating this variable because previous literature supports the strength of perceived susceptibility as a possible predictor of mammography use. The responses on the two items, "Disagree," "Strongly Disagree," and "Neutral" together were recoded as "0" to reflect low perceived susceptibility. The responses, "Agree" and "Strongly Agree" combined were recoded as "1" for high perceived susceptibility. For the analysis, the criteria for low perceived susceptibility was a "0" response for both items in the subscale and high perceived susceptibility was a response of a "1" on one or both items. For the categorical predictor variables, a table of cell frequencies was examined to assure that no cells have expected cell frequencies of <5.

The original sample for this study included 294 women. However, a total of 20 cases were dropped due to missing data. Data was considered missing if 15% or more of the scale responses were unanswered. If 15% or less of the data were missing on all the scales except the Economic Adequacy Scale, the individual's average item score was substituted for each scale. For the Economic Adequacy Scale the total score was obtained by taking the mean score of the answered items.

The pattern for missing data was checked by performing independent T tests on the group with missing data (dropped group) compared with the group used for the final analyses. The group with missing data (dropped group) (n = 20) was not statistically significant different from the group with no missing data (n = 274) on MS pattern, employment status, ethnicity, marital status, and education level (degree). The final sample size of 274 meets the required minimum sample size to achieve adequate statistical power of at least 0.80 for binary logistic regression analysis (at least 10 times the number of participants as predictor variables) (Warner, 2008).

Question 1

What is the percentage of regular mammography screening in this sample of women with MS?

Descriptive statistics (frequency) were conducted to determine the percentage of women receiving regular (usual) mammography screening (every year).

Question 2

What are the relationships among contextual factors (MS-related functional limitations, age, and education), family history of breast cancer, health beliefs related to mammography (perceived benefits, barriers and susceptibility to breast cancer), personal resources (social support, economic adequacy, and insurance coverage), and annual mammography use among this sample of women with MS?

Pearson correlations for interval-level data and Phi correlation analysis for categorical data were used to examine the relationships among the study variables. Prior to conducting Pearson correlation statistical analysis, data were analyzed to be sure that the following corresponding assumptions are met: 1) the data has a normal distribution; 2) there is homogeneity of variance; and 3) linearity exists in the relationship between the variables.

Question 3

What are the significant predictors among the independent variables of contextual factors (MS-related functional limitations, age, and education), family history of breast cancer, health beliefs related to mammography (perceived benefits, barriers and susceptibility to breast cancer), and personal resources (social support, economic adequacy, and insurance coverage) for the dependent variable of annual mammography screening use (every year) among this sample of women with MS?

a. *Among these factors, which factor most contributes to the likelihood of annual mammography use among this sample of women with MS?*
b. *Among these factors, what are the significant predictors for annual mammography use after controlling for severity of MS-related functional limitations and demographic characteristics (age and education) among this sample of women with MS?*

The bivariate correlation analysis conducted for Question 2 yielded the predictor variables that had significant correlations with the dependent variable, annual mammography use. Only those predictor variables that were significantly correlated with annual mammography use were added to the logistic regression analysis to be consistent with the logistic regression assumption requiring significant relationships between the predictors and the outcome variable (Tabachnik & Fidell, 2013).

Hierarchical logistic regression analysis was conducted to examine Question 3b. Logistic regression is appropriate when the outcome variable (mammography use in past 12 months) is binary or dichotomous and the "goal of the study is to predict membership in a target group from scores on one or several predictor variables" (Warner, 2008, p. 931). In logistic regression the dichotomous outcome variable is most often coded 0 and 1. Logistic regression uses the logit(L_i), the log of odds to produce the results expressed

as an odds ratio, which compares the probability of an event occurring across two different conditions or groups. Prior to identifying the predictors significantly correlated to the outcome variable, mammography use (from Question 2), based on the conceptual model, the following equation to predict odds from the logistic regression model was:

$$Y = \frac{exp^{(a+b1X1+b2X2+b3X3+b4X4+b5X5+b6X6+b7X7+b8X8+b9X9+b10X10)}}{1 + exp^{(a+b1X1+b2X2+b3X3+b4X4+b5X5+b6X6+b7X7+b8X8+b9X9+b10X10)}}$$

Where:

Y = the probability that a case is in a particular category,
Exp = the base of natural logarithms
a = the constant of the equation and,
b = the coefficient of the predictor variables,
X_1 = Severity of Limitations
X_2 = Age
X_3 = Education
X_4 = Perceived benefits/mammography
X_5 = Perceived barriers/mammography
X_6 = Perceived susceptibility to breast cancer
X_7 = Social support
X_8 = Economic adequacy
X_9 = Insurance
X_{10} = Family history of breast cancer

Consistent with the conceptual model, hierarchical logistic regression was conducted entering the significant contextual factor(s) predictor(s) in the first block followed by the significant health belief/mammography and personal resources predictors in the second block.

The overall measure of model fit in logistic regression was assessed by testing the difference between the null model (model with the constant only) and the full model (with k = number of predictor variables and k degrees of freedom (*df*)) using the chi square statistic equation:

$$\chi^2 = (-2LL_{\text{null model}} - (2LL_{\text{full model}}))$$

When chi-square is statistically significant there is less error in prediction when comparing the full model to the null model (Warner, 2008). When the overall model was shown to be statistically significant, the Wald chi-square statistic was used to determine the strength and direction of the predictive ability of the individual predictor variables in the model.

The presence of outliers or cases that did not fit the model was determined by examining the standardized residuals for outliers (ZResid > 1.96 for $p < .05$) and Cook's Distance (< 1) (Field, 2012). In the event that outliers were identified, separate logistic regression analyses were conducted excluding the outlier(s) to assess the influence of the case on the overall integrity of the model.

SUMMARY

This chapter provided a discussion about the methodology that was used to collect and analyze the data in this prospective descriptive correlational study; the study focused on the influence of several factors that may predict the likelihood of mammography use in the past 12 months in a sample of women with MS. Data were collected over a two year period. Data relevant to the predicting factors were collected in the first year of this dissertation study (Year 13 of the longitudinal study) and the data for the outcome variable mammography screening was collected in the second year (Year 14 of the longitudinal study). Binary logistic regression using SPSS 20.0 (IBM, 2011), the statistical analysis appropriate to address the research questions in this study was also discussed in this chapter. Chapter 4 will discuss the findings from the analysis of the data discussed in this chapter.

Chapter 4: Results

This chapter discusses the results of this dissertation study. The first section of this chapter is a description of the sample. This description will be followed by a presentation of the descriptive statistics for all the variables in the study and the results of the analyses for each research question.

SAMPLE

The 274 study participants had a mean age of 59.2 years (*SD* = 9.0). The majority of the participants were White (92.7%), married (66.1%), and had an associates degree or higher (53.9%). The average length of diagnosis with MS was 22.2 years (*SD* = 6.62). About 40% of the participants had a diagnosis of relapsing-remitting MS, 13.5% had primary-progressive MS, 21.5% had secondary progressive MS, 10.9% had benign-sensory MS, and 8.8% were unable to choose the type of MS they had. Table 2 is a summary of the demographic characteristics of this study sample.

Table 2

Demographic Characteristics of the Sample (N = 274)

Demographic Variable	Value %	n	Mean(SD)	Range
Age		274	59.3(8.9)	39-85
Years Diagnosed with MS		274	22.2(6.6)	13–52
Marital Status				
Married	66.1	181		
Living with a significant other	1.8	5		
Never Married	5.8	16		
Divorced/Widowed/Separated	26.2	72		
Ethnicity[a]				
White	92.7	242		
Black, African American	3.8	10		
American Indian or Alaska Native	.8	2		
Are you Latino?[a]				
Yes	2.7	7		
No	97.3	248		
Employment Status[a]				
Unemployed due to disability	28.5	78		
Retired/age	30.7	84		
Full/Part Time	25.9	71		
Laid Off	1.8	5		
Full-time Homemaker	13.1	36		
Education Level[a]				
High School, GED	35.2	92		
Associates/Bachelors degree	40.6	106		
Graduate degree (MA/PhD)	12.5	33		
Years of Education			14.4(2.7)	2-22
MS Disease Pattern				
Benign sensory	10.9	30		
Relapsing-remitting	40.1	110		
Primary progressive	13.5	37		
Secondary progressive	21.5	59		
Progressive relapsing	5.1	14		
Unable to choose	8.8	24		

[a]Indicates missing data and therefore will not add up to 274.

Analysis

Descriptive Statistics For Study Variables

Contextual Factors (Age, Years of Education, and Severity of Limitations)

The mean age of this study sample was 59.3 years old (*SD* = 8.9) with a wide age range of 39 years to 85 years of age. This study sample is highly educated, as the mean number of years of school for this sample was 14.4 years. The years of education ranged from 2 years to 22 years of school. The mean score of 17.6 (*SD* = 9.5) for the responses on the Incapacity Status Scale, measuring severity of functional limitations, indicates a relatively low level of overall severity of functional limitations for this sample. On the Incapacity Status Scale the minimum and maximum score (lower score = lower level of functional limitations) is 0.0 to 65, respectively, and for this sample the minimum score was 1.0 and the maximum score was 49.1.

Family History of Breast Cancer (Mother, Sister)

The majority of this sample reported not having an immediate family (mother, sister) history of breast cancer. Over 83% responded "no" to the survey question regarding presence of a breast cancer history in a mother or a sister.

Breast Cancer Screening Belief Scales for Women with Disabilities (BCSBSWD)

On the 5-item Benefits/mammography subscale, scores for the sample ranged from 5 to 25 (possible subscale score range is 5–25). The sample's mean score of 20.2 (*SD* = 3.7) on this subscale suggests that as a group, the women perceived a relatively high level of benefit to mammography screening. The 7-item Barriers/mammography subscale had a mean score of 12.8 (*SD* = 4.6) and a response range of 7 to 27 (possible maximum is 35) suggesting lower perceived barriers to mammography screening. On this subscale, "Having a routine mammogram or X-ray of the breast would be painful" was

the biggest barrier (21%) reported by the women followed by "hard to get positioned for the mammography machine" (17.2%). The women in this study reported relatively low perceived susceptibility to developing breast cancer. On the perceived susceptibility to breast cancer subscale, 87.2% of the women in this study reported low susceptibility to developing breast cancer.

Personal Resources (Social Support, Economic Adequacy, and Insurance Coverage)

The scores on the PRQ questionnaire measuring perceived social support, were widely dispersed, ranging from 49 to 175 (possible subscale range is 25–175) and the mean score was 140.8 (*(SD* = 25.97). This distribution of scores for the sample suggests that the women in this sample perceived a relatively high level of social support. On average, most of the women reported having a relatively high perceived economic adequacy. The average item score was 3.21 with the possible score range for this scale being 1 to 4. For this sample, the scores ranged from 1.4 to 4.0. The majority of the women in this study reported having insurance coverage. Approximately 97% reported having insurance coverage and only 3.3% reported no coverage. Table 3 is a summary of the descriptive statistics.

Table 3

Summary of Descriptive Statistics of Study Instruments (N = 274)

Instrument/Scale	Study Variable	Mean (SD)	Percent	Score Range Sample	Score Range For Instrument
Age (survey question)	Age	59.3 (8.9)		39–85	NA
Years of Education	Years of Education	14.4 (2.7)		2–22	NA
Incapacity	Severity of Limitations	17.5 (9.5)		1.0-49.1	0–64
BCSBSWD (3 subscales)	Perceived Benefits/ Mammography	20.2 (3.7)		5.0–25	5–25
	Perceived Barriers/ Mammography	12.3 (4.6)		7.0–27	7–35
	Perceived Susceptibility				
	High Susceptibility		12.8		
	Low Susceptibility		87.2		
Personal Resource Questionnaire (PRQ)	Personal Resources Social Support	140.8 (26.0)		49–175	25–175
Economic Adequacy	Personal Resources Economic	3.2 (0.7)		1.4–4.0	1–4.0
Insurance Survey Question	Personal Resource Insurance Coverage				
	No		3.3		
	Yes		96.7		
Survey Question (Immediate Family History of Br CA)	Family History of Br CA		83.2		
	No		16.8		
	Yes				
Survey Question (Mammography)	Usual Frequency of Mammography				
	Every year		62.0		
	Every 2 years		24.5		
	Less frequently than every 2 years		13.5		

QUESTION 1

What is the percentage of regular mammography screening in this sample of women with MS?

Sixty two percent of the women in this study reported having had a mammogram in the last year.

QUESTION 2

What are the relationships among contextual factors (MS-related functional limitations, age, and education), family history of breast cancer, health beliefs related to mammography (perceived benefits, barriers and susceptibility to breast cancer), personal resources (social support, economic adequacy, and insurance coverage), and annual mammography use among this sample of women with MS?

Bivariate Correlations Among Predictor Variables

Table 4 presents the correlations among the study variables. Although there were many statistically significant correlations among the predictor variables, in general, these correlations were relatively small. Among the predictor variables, severity of functional limitations had the strongest negative correlation with social support (r = -.34 p < .01), followed by perceived economic adequacy (r = -.29 p < .01), and education level (r = -.15 p < .05). Severity of functional limitations had a significant positive correlation with perceived barriers to mammography (r = .25 p < .01). With respect to health beliefs, perceived barriers to mammography correlated negatively with perceived benefits to mammography (r = -.40 p < .01), perceived economic adequacy (r = -.34 p < .01), and

social support (r = -.26 p < .01). Perceived barriers had a significant positive correlation with perceived susceptibility to breast cancer (r = .12 p < .05).

Perceived susceptibility to breast cancer was positively and significantly correlated with immediate family history of breast cancer (*Phi* = .24 p < .01). Economic adequacy was significantly correlated with all the other predictor variables in the study except with perceived susceptibility to breast cancer (r = .00) and immediate family history of breast cancer (r = .05).

Bivariate Correlations Between Predictor Variables and Mammography Screening

Among the contextual factors only severity of functional limitations was significantly correlated with annual mammography use (r = -.16 p < .01). Although the correlation was small, an increase in self- reported severity of functional limitations was associated with a decrease in annual mammography use. Age and education level were not significantly correlated with annual mammography use.

Although many of the predictor variables had statistically significant correlations with annual mammography use, these effect sizes were small. The predictors that were positively and significantly correlated with annual mammography use included economic adequacy (r = .23 p < .01), immediate family history of breast cancer (r = .17 p < .01), and perceived susceptibility to breast cancer (r = .16 p < .01). The predictors that were negatively and significantly correlated with annual mammography use included, perceived barriers to mammography screening (r = -.22 p < .01) and severity of functional limitations (r = -.16 p < .01). Age, years of education, perceived benefits of mammography screening, social support, and insurance coverage were not significantly correlated with annual mammography use in this sample.

Table 4

Summary of Bivariate Correlations Among Study Variables (N = 274)

	1	2	3	4	5	6	7	8	9	10	11
1. SFL	1										
2. Age	.10	1									
3. Education	-.15*	-.05	1								
4. Family HX of Br CA	.04	.10	-.08	1							
5. Perceived Benefits/mammo	-.11	.07	.00	.02	1						
6. Perceived Barriers/mammo	.25**	-.01	-.06	.04	-.40**	1					
7. Perceived Susceptibility to Br CA	-.02	.01	.05	.24**a	-.18**	.12*	1				
8. Social Support	-.34**	.10	.16*	.00	.25**	-.26**	-.06	1			
9. Economic Adequacy	-.29**	.23**	.25**	.05	.30**	-.34**	.00	.38**	1		
10. Insurance	-.00	.06	-.07	.03a	.05	-.01	.01a	.05	.14*	1	
11. Mammo	-.16**	.06	.09	.17**a	.09	-.22**	.16**a	.10	.23**	.11a	1

* = $p < .05$; ** = $p < .01$; a = Phi correlation; SFL = Severity of Limitations; Family HX of BR CA = Family History of Breast Cancer

QUESTION 3

What are the significant predictors among the independent variables of contextual factors (MS-related functional limitations, age, education), family history of breast cancer, health beliefs related to mammography (perceived benefits, barriers and susceptibility to breast cancer), and personal resources (social support, economic adequacy, and insurance coverage) for the dependent variable of annual mammography screening use among this sample of women with MS?

a. Among these factors, which factor most contributes to the likelihood of annual mammography use among this sample of women with MS?

b. Among these factors, what are the significant predictors for annual mammography use after controlling for severity of MS-related functional limitations and demographic characteristics (age and education) among this sample of women with MS?

Logistic Regression Results

Logistic regression to predict the likelihood of annual mammography use in this sample was performed using the predictor variables that had significant bivariate correlations with annual mammography use (Question 2). Logistic regression assumes a significant relationship between the dependent variables and the outcome variable (Tabachnick & Fidell, 2013). Based on the results of the correlational analysis in Question 2, the following five predictor variables were significantly correlated with annual mammography use: severity of functional limitations, family history (mother, sister) of breast cancer, perceived barriers to mammography, perceived susceptibility to breast cancer, and perceived economic adequacy. The following predictor variables were not included in the logistic regression model(s) since the bivariate correlations with

annual mammography use were not statistically significant: age, education level, perceived benefits related to mammography, and insurance coverage. The most significant predictor among the significant predictor variables was perceived susceptibility to breast cancer (AOR 3.0 95%CI (1.1–8.0). Hierarchical logistic regression was conducted to examine Question 3b.

Hierarchical Logistic Regression Results

To address Question 3b, predictor variables were entered into the models hierarchically in accordance with the overall conceptual framework presented in Chapter 1. In the first step of the logistic regression analysis (Model 1), the effect of severity of functional limitations on annual mammography use was examined. Therefore, Model 1 consisted of the constant only where all the b values are set to zero and the predictor variable, severity of functional limitations. In Model 2, the full model, the remaining predictor variables (family history of breast cancer, perceived barriers to mammography screening, perceived susceptibility to breast cancer, and perceived economic adequacy), were added to the logistic regression model, while adjusting for severity of functional limitations.

Model Fit

The logistic regression model fit with severity of functional limitations entered into the regression model in the first block, was tested using the significant difference between the initial chi-square for the null model and the model with severity of functional limitations added (357.92–352.12) (χ^2 (1, N = 274) = 5.80, p < .05). This indicates a significant improvement in the model fit when the severity of functional limitations predictor variable is added to the logistic regression model.

In Model 2, the predictor variables (family history of breast cancer, perceived barriers to mammography screening, perceived susceptibility to breast cancer, and perceived economic adequacy) were entered into the logistic regression after controlling for the severity of functional limitations variable (full model). The full model run with the remainder of the predictor variables was significantly different (χ^2 (5, N = 274) = 36.32, p < .001) from the model run with only the severity of functional limitations predictor and the constant. This indicates an improvement in the overall model fit when including the remainder of the predictor variables in the full model.

The Hosmer and Lemeshow Test, another *goodness of fit* test to assess model fit, was non-significant for both Model 1 and 2 (p = .40 and p = .06). Non-significance in the Hosmer and Lemeshow Test indicates that there was no statistically significant difference between the observed and the predicted data; thus supporting good model fit for the full model when controlling for severity of functional limitations (Tabachnick & Fidell, 2013; Warner, 2008).

Nagelkerke R Square

The Nagelkerke R Square Test for the approximation for the coefficient of determination R^2, was used for this logistic regression analysis. In the model with only severity of limitations in it, the estimated R^2 was .03 *or 3%* which suggests a relatively weak relationship between the predictor(s), in this case, severity of functional limitations and the prediction (annual mammography use) (Warner, 2008) When controlling for severity of functional limitations, the full model had an R^2 of .17, or 17%, which suggests a relatively weak relationship between the predictors in the full model and annual mammography use.

Model 1 Results

The Wald statistic was used to test whether severity of functional limitations significantly predicted annual mammography use in the initial model (with the constant only). The results of the Wald statistic showed that for the severity of functional limitations significantly contributed to predicting annual mammography use in this sample [(χ^2 (1, N = 274) = 5.80, p < .05)]. Although statistically significant, the odds ratio for severity of functional limitations as a predictor for annual mammography use was .97. This finding means that women in this sample who reported higher severity of MS-related functional limitations were only slightly less likely (.97 times) to get annual mammograms as women who reported less severe MS related functional limitations.

Individual Predictor Variable Contribution to Outcome Prediction/Model 2

Table 5.1 shows a summary of the Model 1 and 2 regression coefficients, Wald statistics, odds ratio, adjusted odds ratio, and 95% confidence intervals for odds ratios for each of the predictor variables when adjusted for severity of functional limitations. Although in Model 1, severity of functional limitations was a significant positive predictor of annual mammography use (OR = .97, 95% CI [.942, .994] p < .05], it did not significantly predict annual mammography use when the remaining predictor variables were added to the final model (AOR = .98, 95% CI [.96, 1.01] p = .25). The significant predictors of annual mammography use, adjusted for severity of functional limitations were, perceived susceptibility to breast cancer, immediate family history, perceived economic adequacy, and perceived barriers to mammography screening.

When adjusted for severity of functional limitations, perceived susceptibility to breast cancer was a strongest predictor of annual mammography use [χ^2 (1, N = 274) = 5.00, p < .05] (AOR = 3.0, 95% CI [1.1, 8.0], p < .05). High perceived susceptibility was associated with higher odds of mammography use; women reporting high perceived

susceptibility were 3.0 times more likely to report annual mammography use than women reporting low susceptibility to breast cancer.

Immediate family history was a strong positive predictor of mammography use [χ^2 (1, N = 274) = 4.7, p < .05] (AOR = 2.5, 95% CI [1.19, 5.68]). Women who reported an immediate family history were 2.5 times more likely to get an annual mammogram than women who reported no family history, when adjusted for severity of functional limitations.

Perceived economic adequacy was significantly and positively associated with mammography use [χ^2 (1, N = 274) = 4.55, p < .05] (AOR = 1.56, 95% CI [1.04, 2.36]). Women reporting high perceived economic adequacy were 1.6 times more likely to get annual mammograms than women reporting low perceived economic adequacy, when adjusted for severity of functional limitations.

Perceived barriers to mammography screening [χ^2 (1, N = 274) = 7.01, p < .01] was a significant negative predictor of mammography use, when adjusted for severity of functional limitations. Although perceived barriers to mammography was a significant predictor the association between barriers to mammography screening and mammography use was relatively weak (AOR = .92, 95% CI [.86, .98]). The odds ratio of .92 indicates only an 8% reduction in the odds of getting an annual mammogram for women reporting barriers to mammography screening compared with women reporting no barriers to screening. Therefore, for this sample, women who reported higher perceived barriers were only slightly less likely to get annual mammograms than women who reported few or no perceived barriers to mammography.

Table 5.1

Summary of Logistic Regression of Annual Mammography Use as a Function of Immediate Family History, Perceived Barriers to Mammography, Perceived Susceptibility to Breast Cancer, Perceived Economic Adequacy when Controlling for Severity of Functional Limitations (N = 274)

Model 1 Predictor Variable	*B*	SE	Wald x^2 test	df	Odds Ratio	P	95% CI Lower	95% CI Upper
Severity of Functional Limitations (MS-related)	.033	.014	5.69	1	.968	.017*	.942	.994
Constant	1.099	.277	15.728	1	3.00	.001**		

Model 2 Predictor Variable	*B*	SE	Wald x^2 test	df	Adjusted Odds Ratio	P	95% CI Lower	95% CI Upper
Severity of Functional Limitations	-.02	.02	1.3	1	.98	.25	.955	1.01
Immediate Family History	-.91	.42	4.7	1	2.5	.03*	1.1	5.7
Perceived Barriers to Mammography	-.08	.03	7.0	1	.92	.01*	.86	.98
Perceived Susceptibility to Breast Cancer	1.11	.50	5.0	1	3.0	.03*	1.1	8.0
Perceived Economic Adequacy	.45	.21	4.5	1	1.6	.03*	1.0	2.4

*$p < .05$; ** $p < .01$
CI= Confidence Interval

The following is the equation for prediction for the full logistic regression model:

$$Y = \frac{exp^{(1.105+(-.017)(X1)+(-.084)X2+(1.105)X3+(.447)X4+(-.913)X5}}{1 + exp^{(1.105+(-.017)(X1)+(-.084)X2+(1.105)X3+(.447)X4+(-.913)X5}}$$

Where:
Y = the probability of getting an annual mammogram
Exp = the base of natural logarithms
X1 = severity of functional limitations
X2 = perceived barriers to mammography
X3 = perceived susceptibility to breast cancer
X4 = perceived economic adequacy
X5 = immediate family history of breast cancer

Classification of Cases

The classification table indicates the degree to which the outcome variable has been correctly predicted (Tabachnick & Fidell, 2013). For the initial null model the overall percentage of correctly predicted was 62.7%. When severity of functional limitations was added to the model, there was only a slight improvement in the overall percentage of the probabilities of annual mammography use that was correctly predicted (63.8%). When the remainder of the predictor variables was included in the model for the full model, there was a relatively small improvement in the model's ability to correctly predict annual mammography use. The overall percentage of correct predictions for the full model was 69.4%.

Identifying Cases Not fitting the Model

The casewise list was examined for any outlying cases or cases that did not fit the model, as these outliers may negatively impact the integrity of the overall model (Tabachnick & Fidell, 2013; Warner, 2008). The standardized residuals (ZResd) were inspected for any case exceeding Z > 1.96 (.05 significance level). Only one case (#30) was identified as an outlier. A logistic regression analysis was run excluding this case to

assess whether this case significantly affected the results of the analysis. There were no significant changes in the results of the logistic regression when excluding this case and therefore case #30 was retained for the final logistic regression model.

Summary

This chapter discussed the findings from the statistical analysis of the data to predict annual mammography use in this sample of women. The study sample included 274 women recruited from the ongoing longitudinal study on health promotion for persons with MS. This sample, whose average age was 59.2 years, was primarily White (92.7%), married (66.1%), and had a relatively high education level (53.9% with at least an associate degree).

The majority (62%) of the women in this sample responded that they "usually" received annual mammograms. Pearson and Phi correlations conducted to examine the relationships among the study variables yielded generally small to moderate correlations. There were small statistically significant correlations between the predictor variables and annual mammography use (severity of MS-related functional limitations, barriers to mammography use, perceived susceptibility, immediate family history, and economic adequacy).

Hierarchical logistic regression was conducted to identify the predictor variables that most contributed to the likelihood of annual mammography use when controlling for severity of limitations. Perceived susceptibility to breast cancer contributed most to the likelihood of annual mammography use (AOR 3.0, 95% CI [1.1, 8.0], $p < .05$, followed by immediate family history (AOR = 2.5, 95% CI [1.19, 5.69] $p < .05$). Perceived economic adequacy and to a lesser degree, perceived barriers to mammography were significant positive predictors (AOR 1.6, 95% CI [1.0, 2.4, $p < .05$; AOR .92, 95% CI

[.86, .98], $p < .01$, respectively) of annual mammography use. Analysis of this hierarchical logistic regression model showed adequate fit, with an improvement in the ability of the model to predict the outcome, annual mammography use at each step of entering the predictor variables.

Chapter 5: Summary, Discussion, Limitations, Implications, Future Research, and Conclusion

This chapter includes a summary of this study and a discussion of the findings as compared with other prevailing research, limitations of this study related to methodological issues, implications of this study as it relates to the nursing profession, and suggested future research in this area.

SUMMARY OF THE STUDY

The purpose of this dissertation study was to examine the influence of severity of MS-related functional limitations, demographic characteristics (age and education), family history of breast cancer, health beliefs related to mammography screening (perceived benefits, barriers, and susceptibility to breast cancer), and personal resources (social support, economic adequacy, and insurance coverage) on the likelihood of annual mammography screening use in a sample of women with MS.

Using the Breast Cancer Screening Model for WWCDC as the conceptual framework, this study used a prospective descriptive correlational design in which the data were collected over two years (Time 13 and Time 14 of the larger ongoing longitudinal parent study). Data were collected in Time 13 and 14 through the annual survey questionnaire mailed to participants of an ongoing longitudinal study of health promotion and quality of life among persons with MS, *Maximizing Health with Multiple Sclerosis*. The instruments used in this dissertation study included those administered as part of the annual survey questionnaire for the parent study (RO1NR003195) as well as items and instruments specifically related to breast cancer screening. The following self-report instruments were used in Time 13: 1) Background Information Sheet to measure demographic characteristics 2) Incapacity Status Scale (Kurtzke, 1981) to measure

severity of MS-related functional limitations 3) Personal Resource Questionnaire (PRQ) (Weinert & Brandt, 1987) to measure social support as part of personal resources 4) Economic Adequacy Scale (Lobo, 1995) to measure perceived adequacy of financial resources as part of personal resources 5) Three BCSBSWD subscales, Perceived Benefits to Mammography, Perceived Barriers to Mammography, and Perceived Susceptibility to Breast Cancer to measure health beliefs specific to mammography screening. The following self-report instruments were used in Time 14: 1) Background Information Sheet for demographic information 2) Survey questions regarding immediate family history, insurance coverage, and mammography use (usual).

A nonprobability sample of 274 women participating in an ongoing longitudinal study on health promotion for persons with MS in Texas was used for this study. The original sample for data analysis consisted of 294 women, however, 20 women were dropped from the study due to missing data. The inclusion criteria included the following: 1) a diagnosis of MS for at least six months; 2) at least 39 years of age at Time 13; and 3) no history of breast cancer.

Descriptive statistical analysis was conducted to investigate the annual mammography rate in this sample as well as the characteristics of the responses to the instruments used to measure the study variables. Pearson and Phi correlations were performed to examine the relationships among all the study variables. Simultaneous logistic regression was conducted to identify the predictor variables that significantly predicted annual mammography use, including the predictor variable that contributed most to the likelihood of annual mammography use in this sample. In addition, the investigator conducted a hierarchical logistic regression, consistent with the conceptual model, to identify which predictor variables significantly predicted annual mammography use, when controlling for the effects of severity of functional limitations.

The results of the descriptive data analysis indicated that this sample was comprised of relatively highly educated (53% with at least an associate degree), primarily White (92.7%), married (66.1%), women. The age range in this sample was 39-85 years of age, with the average age of 59.2 years.

Descriptive statistics on the data also showed that 62% of the women in this study reported that they "usually" received annual mammograms. Scores on the Incapacity Status Scale measuring severity of MS-related functional limitations were relatively low indicating a relatively low level of functional limitations (M = 17.6, SD = *9.5)*. Most of the women (83.2%) reported having no immediate family history (mother, sister). On the BCSBSWD Perceived Benefits/Mammography subscale the total mean score of 20.2 (SD = 3.7) (maximum possible score of 35) and the low total mean score of 12.3 (SD = 4.6) (maximum possible score of 25) on the Perceived Barriers/Mammography subscale suggests that these women perceived relatively high levels of benefits and low levels of perceived barriers to mammography. On the Perceived Susceptibility to Breast Cancer subscale, only 12.8% reported high perceived susceptibility to breast cancer. With respect to personal resources, a high total mean score on the PRQ, measuring social support (M = 140.8 SD = 26) and high average item scores on the Economic Adequacy Scale suggests that the women in this sample perceived high levels of social support and high perceived adequacy of financial resources among these women. In addition, most of the women (96.7%) reported having insurance coverage.

Pearson and Phi correlation analysis were conducted to examine the relationships between the study variables. In general the bivariate correlations among the study variables were small to moderate. The most notable significant bivariate correlations were the between the following: 1) severity of functional limitations and perceived barriers to mammography (r = .25 p < .01) 2) severity of functional limitations and both

social support and economic adequacy (r = -.34 p < .01; r = -.29 p < .01, respectively) 3) social support and both perceived benefits and perceived barriers to mammography (r = .25 p < .01; r = -.26 p < .01, respectively) 4) perceived economic adequacy and both perceived benefits and barriers to mammography (r = .30 p < .01; r = -.34 p < .01, respectively).

Bivariate correlations were conducted between the predictor variables and the outcome variable, annual mammography use. Although the correlations were small, perceived barriers to mammography (r = -.22 p < .01) and severity of functional limitations (r = -.16 p < .01) were significantly and negatively correlated, while perceived economic adequacy (r = .23 p < .01) and immediate family history of breast cancer (r = .17 p < .01) were positively and significantly correlated with annual mammography use.

Hierarchical logistic regression was conducted to identify those variables that contributed most to the likelihood of annual mammography use in this sample and to identify those variables that contributed most to the likelihood of annual mammography when controlling for the influence of severity of MS-related functional limitations (consistent with the conceptual model). Consistent with the assumptions for logistic regression, only the predictor variables that were significantly correlated with annual mammography use were added to the logistic regression models. The following five predictor variables were used for the logistic regression analysis: severity of functional limitations, immediate family history of breast cancer, perceived barriers to mammography, perceived susceptibility to breast cancer, and perceived economic adequacy.

Results from the hierarchical logistic regression showed that when adjusted for severity of functional limitations, perceived susceptibility to breast cancer was a significant positive predictor and contributed the most to the likelihood of annual

mammography use (AOR = 3.0, 95% CI [1.1, 8.0], $p < .05$) followed by immediate family history (mother or sister) (AOR 2.5, 95% CI [1.1, 5.7], $p < .05$) perceived economic adequacy (AOR = 1.6, 95% CI [1.0, 2.4], $p < .05$) and perceived barriers to mammography (AOR = .92, 95% CI .86, - .98). Severity of functional limitations was not a significant predictor of annual mammography use in this sample (AOR = .98, 95% CI [.96, 1.0], $p = .25$).

DISCUSSION

Mammography Use

Sixty-two percent of the women in this study reported *usually* getting mammograms once a year, 24.5% reported getting mammograms every two years, and 13.5% reported getting mammograms less frequently than every two years. The annual mammography rate reported by the women in this study was substantially higher than the mammography rates for both WWCDC and women in the general population found in previous research studies (Chan et al., 1999; Pace, He, & Keating, 2013; Shabas & Weinreb, 2000; Schootman & Jeffe, 2003). Shabas and Weinreb (2000) found a 50% annual mammography rate for women with MS. Similarly in the general population, a recent study to examine trends in mammography screening rates following the USPSTF guideline changes in 2009, showed a 54% annual mammography rate for women 40 years or older (Pace et al., 2013).

Most of the recent mammography research specifically targeted to WWCDC use national population-based surveys, which use the USPSTF mammography guidelines (every one to two years) Courtney-Long et al., 2011; Reichard, et al., 2011), making it difficult to make comparisons regarding the findings of this study to these other studies.

Therefore, for the purpose of comparison in this discussion, the mammography rate in the every one to two year interval was calculated for this study and was found to be 86.5%. This finding differs greatly from the 72.2% mammography rate for WWCDC compared to 77.8% in the general population reported by Courtney-Long and colleagues (2011) in their recent study using population-based data to compare mammography use between women with and without disabilities and other similar studies (Armour et al., 2009; Chevarley et al., 2006; Reichard et al., 2011; Wei et al., 2006).

The relatively high mammography rate (every two years) found in this study exceeds the *Healthy People 2020* target goal of 81%. Furthermore, these findings support the findings of other studies that report similarly high mammography rates for WWCDC (Diab & Johnston, 2004; Frey et al., 2003; Liu & Clark, 2008; Nosek & Howland, 1997). For example, in a national study of utilization of preventive services by persons with MS, Frey and colleagues (2003) reported higher overall mammography rates, (77.3%) for women 40 years and older compared to the mammography rates (51.1%) for the general population.

The finding that the women in this dissertation study have a higher annual mammography rate than women in the general population may be possibly attributed to a number of factors. The women in this study were "survivors" of a larger, ongoing longitudinal health promotion study for persons with MS who may have an increased sense of health responsibility and awareness about health promoting behaviors including mammography screening. The demographic characteristics of these women may have also played a role in the high mammography rate in this study. Most of the women in this study were White (92.7%), highly educated (mean years of education = 14.4), and married (66.1%), which are associated with higher mammography use for WWCDC and the general population (Chevarley et al., 2006; Nosek & Howland, 1997 Scheuler et al.,

2008; USDHHS, 2007). Likewise, the vast majority of the women in this study had insurance coverage and probably a usual source of care, which again are known positive correlates of mammography use (Ahmed et al., 2009; Courtney- Long et al., 2011; Parish & Huh, 2006; Wei et al., 2006). In summary, the results of this study may reflect a higher level of awareness or sensitivity to engaging in health promoting behavior, including annual mammography screening by the women in this study that may not be characteristic of all WWCDC.

Contextual Factors: Age, Education, Severity of MS-related Functional Limitations

Age and Education

Age did not correlate significantly with annual mammography use in this study sample (r = 0.06). In this study, 53.7% of the women 40–49 years old, 62.7% of women 50–64 years old, 66.7% of women 65–74 years old, and 60% of women 75 years old or older reported *usually* getting a mammogram every year. There was no significant difference in mammography rate by age group (p = .61). The prevailing literature shows a curvilinear relationship between age and mammography where younger (40-49 years old) and older women (65 years old or older) are less likely to get mammograms than women 50–64 years old (Breen, et al., 2011; Bluestein & Weiss, 1998; Chevarley et al., 2006; Frey et al., 2003; Gierisch et al., 2010; Ostbye et al., 2003). The presence of a curvilinear relationship between age and mammography use (not tested in this dissertation study) may partially explain the weak non-significant correlation observed in this study. When comparing mammography rates of women 50–64 to those of women 40–49 years old the mammography pattern by age in this study is consistent with a study using a similar population with MS, in which women 55 years or older were 2.2 times were likely to get mammograms than women 35–54 years old (Frey et al., 2003).

Education (years of education) did not significantly correlate with annual mammography screening (r = .09). This finding supports the findings from some studies (Ahmed et al., 2009; Clark et al., 2009; Frey et al., 2003) and varies from the numerous studies that show a significant positive relationship between education level and mammography use (Breen et al., 2011; Courtney-Long et al., 2011; Peek & Han, 2004; Scheuler et al., 2008; Schootman & Jeffe, 2003). Although Courtney-Long and colleagues showed a difference between the likelihood of getting a mammogram for WWCDC by education level, this difference was relatively small with high school graduates or those with some college being only15% less likely to receive mammograms than college graduates. The sample in this dissertation study reported a relatively high education level (M = 14.2 years of education), with low variability in education levelwhich may partially explain the lack of a significant relationship between education and annual mammography use.

Severity of MS-Related Functional Limitations

This study found that in the bivariate analysis, severity of MS-related functional limitations was significantly and negatively correlated to annual mammography use (r = -.16 p < .01). However, severity of functional limitations did not remain as a significant predictor of annual mammography use when other predictor variables were added to the hierarchical logistic regression analyses. These findings do not support previous evidence for disability as an independent predictor of mammography use (Armour et al., 2009; Chan et al., 1999; Courtney-Long et al., 2011; Frey et al., 2003; Iezzoni et al., 2000; Legg et al., 2004; Reichard et al., 2011; Thierry, 2000). Instead, it supports previous research suggesting that other factors may have greater influence on regular mammography behavior (Clark et al., 2009; Liu & Clark, 2008; Nosek & Howland, 1997) and that the

influence of functional limitations is dependent on the type of impairment (Ahmed et al., 2009; Iezzoni et al., 2001).

The findings of this study may also be somewhat consistent with the evidence suggesting that degree of functional limitations has a negative influence on mammography behavior only at high levels of functional impairment (Chevarley et al., 2006; Iezzoni et al., 2001). For example, Chevarley and colleagues found that only women 65 years or older, with three or more physical limitations were less likely to get mammograms than those without limitations. In contrast, women with only one or two reported functional limitations were as likely as women without limitations to be screened.

The finding that severity of limitation is not predictive of annual mammography use in this study may be attributed to several factors. The relatively low levels of functional limitations reported by the women in this sample may have contributed to this lack of significance. It is possible that the women with greater limitations may have dropped out of the study prior to Year 13 and 14 data collection. Furthermore, although the instrument measuring severity of limitations (ISS) measures multiple types limitations, it does not measure a woman's ability to stand for extended amounts of time, which would be more relevant to mammography screening.

Family History (Mother, Sister)

The presence of an immediate family history of breast cancer was positively associated and was a significant predictor of annual mammography use in this study. Women in this study were 2.5 times more likely to get annual mammograms if they reported having an immediate family history of breast cancer than if they had no family history. This expected finding supports work by other researchers, who have

demonstrated a strong predictive ability of family history of breast cancer on mammography use (Haber et al., 2012; Murabito et al., 2001; Townsend et al., 2012). Haber and colleagues reported that women with a family history had the highest repeat mammography rate; women whose mothers or sisters had breast cancer had a significantly higher repeat mammography rate over a six-year interval than women without a family history of breast cancer. Similarly, in an earlier study of repeat mammography use of women in the general population, Murabito and colleagues found that women with a positive family history of breast cancer were 3.2 times more likely to get a repeat mammogram than those without a family history.

Health Beliefs Related to Mammography

Perceived Benefits and Barriers to Mammography

In general, most of the women in the study reported high perceived benefits and low perceived barriers related to mammography screening. Although little is known about how beliefs related to mammography are associated with mammography among WWCDC, this study is consistent with the evidence that women with disabilities recognize the importance of getting a mammogram in comparison with other medical procedures (Clark et al., 2009). Interestingly, despite recognizing the benefits of mammography screening, a significant number of the women in this study may also have a knowledge deficit regarding the ability of mammography screening to detect an unpalpable lump as well as reduce breast cancer mortality. Twenty-seven percent of the women did not perceive the benefit, "having a mammogram or X-ray of the breast will decrease my chances of dying from breast cancer." Over a third (33.6%) of the women did not report that "having a mammogram will help me find a lump before it can be found by myself or a health professional."

Perceived benefits of mammography and mammography use were positively correlated as expected, but this correlation was low and not statistically significant (r = .09). This may reflect a low variance in the responses on the Perceived Benefits of Mammography subscale. The findings in this study contradict previous studies demonstrating a significant positive correlation between perceived benefits of mammography and mammography behavior (Champion & Skinner, 2003; Lopez et al., 2009; Thomas et al., 1996). Instead, it supports the findings of an earlier integrative review of the literature that showed weak to moderate effect sizes for perceived benefits of mammography and screening behavior (Yarbrough & Braden, 2000) as well as a later study by Lee-Lin and colleagues (2008) who reported that high perceived benefit scores did not correspond with an increase in mammography use in their study of Chinese American immigrants.

The women in this study generally perceived low barriers to mammography screening. The most reported barriers were related to pain (21%) and difficulty in getting positioned for the mammogram machine (17.2%). Studies of women in the general population and different minority groups have reported that pain is a significant barrier to screening (Scheuler et al., 2008). Scheuler and colleagues found in their meta-analysis of the general population that 15.3% of the women in the studies reported pain as a reason for not getting a mammogram, consistent with this dissertation study. The relatively low percentage of women reporting difficulty with positioning related to the mammography machine was initially surprising and seems contrary to previous studies that found this to be a significant barrier for mammography screening (Barr et al., 2008; Becker et al., 1997; Nosek & Howland, 1997). The relatively low level of severity of functional limitations reported by these women may partially explain why more women in this study did not report positioning for the mammogram machine as a barrier. Despite the

relatively low perceived barriers to mammography reported by the women in this study, it is still noteworthy that difficulty in positioning was reported as a barrier by 17% of these women.

Lack of finances and transportation, reported as barriers by WWCDC in several research studies (Barr et al., 2008; Chevarley et al., 2006; Mele et al., 2005; Smeltzer et al., 2007; Thierry, 2004; Yankaskas et al., 2009), were not considered barriers to most of the women in this study. Cost may not have been a barrier since this sample reported having adequate economic resources. The finding that transportation was not a barrier in this study is somewhat surprising although again, it may be reflective of highly functioning women who continue to drive or have adequate resources (family members) to accommodate their transportation needs.

Consistent with prior research in the general population, perceived barriers to mammography were negatively associated with mammography use (Champion et al., 1999; Champion & Menon, 1997; Champion & Scott, 1997; Champion et al., 2008; Lee-Lin et al., 2008; Yarbrough & Braden, 2001). When controlling for severity of functional limitations as a contextual factor, perceived barriers were a significant predictor of annual mammography use in this study. However, the odds of getting a mammogram were only slightly less (AOR = .92) meaning that the likelihood of getting annual mammograms for women reporting high perceived barriers were only slightly less than for women reporting low or no perceived barriers to mammography. These findings provide evidence that although beliefs about barriers to mammography negatively influences annual mammography use in this sample, when combined with other important factors that may influence behavior, these barriers are not enough to predict their likelihood of getting a mammogram.

Over 87% of the women in this study reported low perceived susceptibility to breast cancer. Similar to women in the general population, they may have optimistic bias and underestimate their risk for breast cancer (Katapodi et al., 2004; Katapodi et al., 2009; Weinstein & Nicolich, 1993). In a study comparing perceived and objective risk to breast cancer, Katapodi and colleagues (2009) found that 89% of the women with higher objective risk for breast cancer underestimated their actual risk for breast cancer. Perceiving low susceptibility to breast cancer for these WWCDC may be a protective coping strategy or a denial mechanism rooted in the notion that since they have one chronic illness, they are not likely to develop another condition. Likewise the thought of having to contend with the demands of another illness, breast cancer on top of MS, may lead to feeling overwhelmed or "having too much too handle" (*No Mas*), which may contribute to lower perceived susceptibility to breast cancer and be a barrier to screening (Todd & Stuifbergen, 2011). For WWCDC, having a low perceived susceptibility may be of particular concern since many of these women have higher actual risk factors for developing breast cancer such as increasing age and obesity (ACS, 2013; Chevarley et al., 2006).

Although there was a small significant positive correlation between perceived susceptibility to breast cancer and annual mammography use (*Phi* = .16 $p < .01$), perceived susceptibility to breast cancer emerged as the most significant predictor of annual mammography use for the women in this study when controlling for severity of functional limitations. Women who reported high perceived susceptibility to breast cancer were 3.0 times more likely to get annual mammograms than women who reported low perceived susceptibility. This is consistent with the findings reported by other researchers, who have found perceived susceptibility to be a significant positive predictor

of mammography of women in the general population (Katapodi et al., 2004; McCaul et al., 1996; Yarbrough & Braden, 2001).

Personal Resources: Social Support, Economic Adequacy, and Insurance Coverage

Social Support

Little is known about the influence of social support on mammography behavior among WWCDC. In this study, social support was not a significant predictor of annual mammography use in this study sample. Although, social support was positively correlated with mammography, this association was low and did not reach significance. The finding that social support was not predictive of annual mammography use may be partially attributed to the low variability in the responses by this sample of women, who reported relatively high social support. These findings may also lend support to the inconsistent influence that social support, with its varied conceptualizations, has on mammography screening.

Previous research yields mixed findings for the predictive ability of social support regarding mammography use depending on the type of social support measured in the general population (Allen et al., 1999; Allen et al., 2001; Allen et al., 2008; Jackson et al., 2006; Kang et al., 1994; Katapodi et al., 2002; Messina et al., 2004). While the findings in this study are similar to those described by Kang and colleagues (1999) who reported no relationship between emotional support or instrumental support and mammography use, it contrasts with some or all of the findings of other researchers (Jackson et al., 2006; Messina et al., 2004). Jackson and colleagues studied a group of women who reported having at least one or more medical conditions and found that after controlling for age, education, and daily hassles, women reporting low support from close relationships (friends and family) were significantly less likely to adhere to routine

medical care than women with higher social support. This dissertation study supports some of the findings of Messina and colleagues (2004) who found that emotional/informational support (access to someone who can exchange, empathy, encouragement, guidance, and advice) but not affection support (availability of having someone who makes you feel loved) was associated with increased repeat mammography use.

Economic Adequacy

Economic adequacy was a positive significant predictor of annual mammography use when controlling for MS-related functional limitations in this study. Women reporting high economic adequacy were over one and a half times (AOR 1.56; 95% CI 1.04–2.36) more likely to get an annual mammogram compared to women reporting low economic adequacy. Previous studies that use income as a financial indicator have consistently demonstrated a positive link between income level and mammography behavior in women with and without disabilities (Chevarley et al., 2006; Frey et al., 2003). Several researchers found that WWCDC report economic barriers to mammography related to inability to pay for the mammogram as well as transportation costs (Barr et al., 2008; Chevarley et al., 2006; Yankaskas et al., 2009). In this study economic adequacy was moderately and negatively associated with perceived barriers to mammography screening (r = -.34, p < .01). Since the women in this study reported generally high perceived economic adequacy, it was not surprising to find that a low percentage (5.8%) of women in this study reported "cost" as barrier to mammography.

The influence of having sufficient financial resources to meet one's needs on mammography for WWCDC should not be underestimated considering that a disproportionate percentage of WWCDC live in poverty (Smith, 2008). The financial

expenses uniquely associated with having a chronic and disabling condition such as those related to multiple co-pays for medical care visits, prescriptions, and transportation costs often exceed the fixed incomes on which many WWCDC live (Barr et al., 2008; M. P. Smith ([personal communication, October, 12, 2012])). For women with MS, for example, in 1994, the individual life-time expenditure related to managing MS exceeded $2 million dollars (Whetten-Goldstein, Sloan, Goldstein, & Kulas, 1998). In today's dollars, given the average rate of inflation (2.47), this would amount to roughly over $3 million dollars or about a 50% increase in expenditures over a life-time for a population that is already financially fragile (US Bureau of Labor Statistics, 2013).

Insurance Coverage

Insurance coverage was weakly associated only with economic adequacy in this study (r = .14 p < .05). The unexpected finding that insurance coverage was not associated with mammography use is contrary to the substantial research, which provides evidence for insurance coverage being a strong positive predictor for mammography use both for women with and without disabling conditions (Ahmed et al., 2009; Courtney-Long et al., 2011; Frey et al., 2003; Scheuler et al., 2008; Wei et al., 2006). Ahmed and colleagues, in their study of women with various types of disabilities, reported that the women with public or private insurance were 1.48 and 1.92 (respectively) times more likely to get mammograms than women with no insurance. Similarly, among WWCDC, Courtney-Long and colleagues reported a higher mammography rate for women with insurance compared to those without insurance (74.8% vs 54.1%).

The lack of significance between insurance coverage and mammography use in this study is likely due to the lack of variability in the sample regarding insurance coverage. About 97% of the women reported having at least one type of insurance, which

although consistent with an earlier study of persons with MS by Frey and colleagues (2003), may not be representative of the insurance coverage rate for the overall population of WWCDC.

LIMITATIONS

The findings in this study should be interpreted with caution, as there are several limitations to this study. These include limitations related to sample bias, self-report, instrumentation, and a historical event. These limitations will be discussed in the next section.

Sample

The convenience sample of 274 women in this study was recruited from an ongoing (17 years) longitudinal parent study on health promotion for persons with MS, which may have introduced sample response bias inherent in this type of sample recruitment. Furthermore, the women in this study, as "survivors" of this longitudinal study on health promotion, may have had a heightened sense of health responsibility and therefore been more likely to engage in health promoting behavior. The demographic makeup of this sample may also have contributed to the study findings. This sample was made up of women who were primarily White, highly educated, and reported having adequate economic resources to meet their financial demands. This is significant since education level, being married and White are all significant positive predictors of mammography use (Chevarley et al., 2006; Scheuler et al., 2008). The fact that most of the women reported having a low severity of MS-related functional limitations is reflective of the fact that those participants with more functional limitations may have

dropped out of the study, leaving those who are less functionally limited, especially considering the relatively long average length of diagnosis (22 years) of this sample.

Although the sample was a nonprobability sample, the demographics of this sample are representative of the general population of persons with MS in the US based on the Minden, Marder, Harcott, & Dor (1993) report and a study using national data from the National MS Society (Frey et al., 2003). The sample in this dissertation study had similar demographic characteristics as other studies examining women with MS. For example, in a study by Frey et al., 90% of the women in their sample were White, non-Hispanic, 68.6% had some college and or a college degree, and 67% were married. Therefore, although these demographic characteristics are typical for women with MS, they may not be representative of other women with different chronic disabling conditions (Chevarley et al., 2006).

Instrumentation

Self-Report

Studies examining the validity of using self-report to determine mammography adherence have shown that women may recall whether they have had a mammogram but not recall the specific time frame of when they got their mammogram (Thompson, Taylor, Goldberg, & Mullen, 1999). This inaccuracy in recall may contribute to an overestimation of mammography use by as much as 15–25% (Cronin et al., 2009; Howard, Agarwal, & Lytwyn, 2009). Cronin and colleagues, using data from population-based surveys, found that although self-report was better for women who maintained regular screening, even these women did not always have accurate mammography recall. These authors attribute the over-reporting of mammography use to a "telescoping phenomenon" (Cronin et al., 2009, p. 1703) in which a person recalls the event occurring

more recently than it has. Recall ability may be particularly salient for the women in this study, considering the strong association between MS and cognitive memory impairment, especially long-term memory deficits (Chiaravalloti & DeLuca, 2008; Rao et al., 1991). Consequently, it is possible that the mammography rate reported by these women may be inaccurate and may be inflated. Using self-report measures may not be as reliable as other more objective measures such as medical records for women with cognitive memory impairment.

Responses to self-report instruments may also be influenced by the desire to respond in a socially acceptable manner that is represents the social norms. This may be especially true, in light of the high publicity surrounding breast cancer screening guidelines in recent years. The women in this study were participants of a study on health promotion and quality of life and therefore social desirability may be reflected in their responses to not only mammography use but to all the other instruments in the study questionnaires.

Limitations Related to Instrument Items

The Incapacity Status Scale (ISS) used to measure severity of MS-related functional limitations contained many items that did not measure limitations that would specifically relate to the mammography screening procedure. Only two items were somewhat related (having to do with walking and transferring from wheelchair to bed). Using this instrument therefore may have had an impact on the findings of this study.

Although the BCSBSWD was adequately validated in this population, the perceived susceptibility subscale had inherent limitations. Initially, this subscale contained three items but because the *No Mas* item did not load with the other items in

the scale, it was dropped, creating a two-item scale that was dichotomized to meet the assumptions for logistic regression analysis.

The survey question regarding presence of immediate family history, "Has anyone in your immediate family (mother, sister) ever had breast cancer?" is limiting. Although using mother and sister is appropriate to determine presence of family history, including other relatives such as fathers would be more appropriate. Men develop breast though the incidence of breast cancer is relatively low in men.

Historical Event

After initiating data collection (2009), the USPSTF introduced changes in mammography guidelines, specifically a change in the minimum age to start getting mammograms from 40 to 50 years of age and the frequency to 1–2 years. The ACS, however, did not change their guidelines on minimum age to initiate screening mammography (40 years old) or the frequency (annual) of mammography. The changes in the guidelines by USPSTF, which were highly publicized, may have influenced the responses by the women in this study.

Over the last decade, there have been numerous national and state initiatives to increase awareness and reduce barriers to mammography screening among WWCDC. The findings from some of the earlier studies, which reported lower mammography rates for WWCDC, may not reflect the potentially positive impact of these interventions. Likewise, the positive impact of these efforts may be reflected in the higher mammography rate reported by the women in this study.

STUDY STRENGTHS

While there were several limitations to this study, there were also many strengths. This study was unique from other previous studies on this topic in that it measured health

beliefs about mammography and psychosocial factors (collected in the first year) to predict usual mammography behavior one year later. The temporal ordering of measuring how beliefs and other psychosocial factors influence usual mammography behavior is also a strength of this study design.

Another strength of this study is that unlike many of the prior research studies predicting mammography use in WWCDC, this study examined "usual" mammography as opposed to recent mammography. "Usual" mammography use examines trends in mammography behavior to identify adherence to mammography screening guidelines. Evidence suggests that maintaining a regular mammography regime as recommended enhances the overall detection benefits of mammography screening (Tabar et al., 2003). Unfortunately, WWCDC are less likely than their non-disabled counterparts to maintain a regular on-schedule mammography regime (Clark et al., 2009; Liu & Clark, 2008).

The relatively large sample of women used for this study provides additional strength to this study. While population-based studies assessing rates of mammography use among WWCDC have boasted large samples, most other studies exploring mammography-related attitudes and beliefs of WWCDC have used small convenience samples.

IMPLICATIONS FOR NURSING

This study contains several implications for the nursing profession. Although more than 62% of the women in this study reported usually getting mammograms every year, over a third of these women reported not getting annual mammograms. Furthermore, most of these women reported low susceptibility to breast cancer. In addition, although they reported low barriers to getting a mammogram, the second most reported barrier, unique to WWCDC, was difficulty in positioning for the mammogram.

These findings highlight the need for nursing interventions to increase the proportion of women regularly getting annual mammograms by assessing the individual informational and educational needs of WWCDC and reducing or eliminating prevailing barriers to getting a mammogram.

Nurses may play a pivotal role in educating and navigating WWCDC in multiple health care settings. The differing guidelines that have been highly publicized have the potential of leaving a woman confused about which recommendations to adopt. Nurses are in a key position to reach out to WWCDC and provide essential education about breast cancer screening recommendations and objective breast cancer risk factors to help these women make informed decisions regarding their health.

Nurses can achieve the goal to reduce or eliminate environmental barriers to screening unique to WWCDC by appropriately referring women to mammography facilities that have accommodating mammography equipment and that provide health information formatted for those with visual or hearing impairments. As members of health care teams, nurses together with technicians and other health care professionals need to be trained to be sensitive to the special needs of WWCDC to insure that WWCDC have a positive experience with mammography screening and establish a regular on-time mammography regime. Several resources on accommodating the needs of WWCDC are available through state and federal health agencies for breast cancer screening facilities including health information appropriate for WWCDC (Thierry, Hurtado, Agin, & Bardfield, 2008).

Nurses can also help reduce the financial barriers often reported by WWCDC (Barr et al., 2008; Chevarley et al., 2006) by providing WWCDC with information about reduced or no-cost mammography programs available for low-income, underinsured, and uninsured women including the National Breast and Cervical Cancer Early Detection

Program (NBCCEDP) (CDC, 2013.). In addition to the NBCCEDP, nurses should inform women that insurance coverage for women's preventive health has been extended and cost-sharing has been eliminated as part of the Affordable Care Act.

In addition to helping eliminate environmental and financial barriers to mammography, nurses may have a central role in helping to reduce the overall stress and ubiquitous burden experienced by many women dealing with the multiple challenges inherent in living with a chronic and disabling condition. This overwhelming feeling of having "too much to handle," needs to be addressed by health care providers to improve the likelihood that WWCDC engage in health promoting behaviors, including mammography use (Todd & Stuifbergen, 2011). Efforts to reduce this phenomenon of *No Mas* may include providing resources for social support through social networks (support groups) available in the community.

In summary, nurses have an important role in improving the mammography screening rate in WWCDC. Nurses, through an interdisciplinary approach in collaboration with other health care professionals, need to focus their intervention strategies on eliminating environmental, financial and psychosocial barriers faced by WWCDC through education, navigation, and coordination of resources available to address these barriers to screening.

FUTURE RESEARCH

There are several possible future studies focused on WWCDC and mammography screening and other health promoting behaviors. As this dissertation study did not examine the possible interactions between the predictors and mammography screening use, further research may include potential moderating or mediating effects of health beliefs related to mammography screening, and personal resources on annual

mammography use in WWCDC. Future research using the Breast Cancer Screening Model for WWCDC conceptual framework may also include examining the influence of other potentially important psychosocial factors on regular mammography screening use such as: spirituality; fear; satisfaction with previous mammography experience; general self-efficacy or self-efficacy specific to mammography screening; and *No Mas*. To measure *No Mas,* developing an instrument using focus group data may be warranted. Further research might use a longitudinal study design to examine how certain factors (like the ones used in this study) predict adherence to regular, on-schedule mammography screening use over time. To test the ability of the Breast Cancer Screening Model for WWCDC to predict mammography use in other groups of WWCDC, future studies might incorporate samples of women with a wide array of chronic disabling conditions (e.g. women with arthritis, visual, hearing, and cognitive impairment). Similarly, since little is known about how cultural beliefs influence mammography use in WWCDC, researchers should consider examining the influence of cultural beliefs on regular mammography screening use for ethnically diverse WWCDC. In sum, expanding the diversity of sample characteristics, both in terms of type of disabling conditions, as well as the ethnicity may broaden the theoretical application of the findings of future studies.

CONCLUSION

The findings in this study are consistent with some previous research, documenting that WWCDC get annual mammograms at a rate comparable or higher than the rate for their non-disabled counterparts. As in other research, perceived susceptibility to breast cancer, immediate family history of breast cancer, economic adequacy, and beliefs about perceived barriers to mammography were significant predictors of annual

mammography use in this sample of WWCDC. Although greater functional limitations were not significantly associated with mammography behavior when other factors were considered, greater functional limitations were significantly linked to higher perceived barriers to mammography. There are several methodological limitations in this study. The generalizability of the study findings is limited by the convenience sample consisting of women who were participating an ongoing longitudinal study on health promotion for persons with MS.

As key health professionals, nurses have the responsibility to develop and implement interventions to address the plethora of disability-related barriers to mammography faced by WWCDC. By facilitating mammography screening, as well as other health promoting activities, nurses can be instrumental in reducing the disparity related to breast cancer screening and overall mortality in a growing population of aging women with chronic disabling conditions.

Appendix A

Date: **02/08/10**

PI(s): **Alexa M Stuifbergen** Department & Mail Code: **NURSING SCHOOL**
Heather A Becker **NURSING SCHOOL**
Tracie C Harrison **NURSING SCHOOL**

Title: **Health Promotion and Quality of Life in Chronic Illness**

IRB APPROVAL – IRB Protocol #**2001-10-0059**

Dear: **Alexa M Stuifbergen** **Heather A Becker** **Tracie C Harrison**

In accordance with Federal Regulations for review of research protocols, the Institutional Review Board has reviewed the above referenced protocol and found that it met approval for the following period of time:

Your amendment has been approved from 02/05/2010 – 06/04/2010 . *(expires 12am [midnight] of this date.)*

The following requested changes have been approved:
Amendment: Modify the protocol to delete one set of questions and add another set of questions as described to the survey that will be conducted this year.

NA ☐ **Please use the attached approved informed consent**
NA ☐ **You have been granted waiver of documentation of informed consent in lieu of verbal consent**
NA ☐ **You have been granted waiver of informed consent**

RESPONSIBILITIES OF PRINCIPAL INVESTIGATOR FOR ONGOING PROTOCOLS:

(1) Report **immediately** to the IRB any unanticipated problems.

(2) Proposed changes in approved research during the period for which IRB approval cannot be initiated without IRB review and approval, except when necessary to eliminate apparent immediate hazards to the participant. Changes in approved research initiated without IRB review and approval initiated to eliminate apparent immediate hazards to the participant must be promptly reported to the IRB, and reviewed under the unanticipated problems policy to determine whether the change was consistent with ensuring the participants continued welfare.

(3) Report any significant findings that become known in the course of the research that might affect the willingness of subjects to continue to take part.

(4) Insure that only persons formally approved by the IRB enroll subjects.

(5) Use **only** a currently approved consent form (remember approval periods are for 12 months or less).

(6) **Protect the confidentiality of all persons and personally identifiable data, and train your staff and collaborators on policies and procedures for ensuring the privacy and confidentiality of participants and information.**

(7) Submit for review and approval by the IRB all modifications to the protocol or consent form(s) prior to the implementation of the change.

(9) Notify the IRB when the study has been completed and complete the Final Report Form.

(10) Please help us help you by including the above protocol number on all future correspondence relating to this protocol.

Sincerely,

Jody L. Jensen, Ph.D.
Professor
Chair, Institutional Review Board

Protocol #2001-10-0059 **Approval dates: 02/05/2010 - 06/04/2010**

OFFICE OF RESEARCH SUPPORT

THE UNIVERSITY OF TEXAS AT AUSTIN

P.O. Box 7426, Austin, Texas 78713 · Mail Code A3200
(512) 471-8871 · FAX (512) 471-8873

FWA # 00002030

Date:

PI:

Dept:

Title:

Re: IRB Amendment Approval for Protocol Number

Dear

In accordance with the Federal Regulations for review of research studies, the Institutional Review Board (IRB) reviewed your requested amendment to the above referenced protocol and found that it met the requirements for approval.

Approval for your study expires on . *Expires 12 a.m. [midnight] of this date.*

The following requested changes were approved:

☐ Continue to use the original approved consent form(s).
☐ Use the attached approved informed consent document(s).
☐ You have been granted a Waiver of Documentation of Consent according to 45 CFR 46.117 and/or 21 CFR 56.109(c)(1).
☐ You have been granted a Waiver of Informed Consent according to 45 CFR 46.116(d).

Responsibilities of the Principal Investigator:

1. Report immediately to the IRB any unanticipated problems.

2. Submit for review and approval by the IRB all modifications to the protocol or consent form(s). Ensure the proposed changes in the approved research are not applied without prior IRB review and approval, except when necessary to eliminate apparent immediate hazards to the subject. Changes in approved research implemented without IRB review and approval initiated to eliminate apparent immediate hazards to the subject must be promptly reported to the IRB, and will be reviewed under the unanticipated problems policy to determine whether the change was consistent with ensuring the subjects continued welfare.

3. Report any significant findings that become known in the course of the research that might affect the willingness of subjects to continue to participate.

4. Ensure that only persons formally approved by the IRB enroll subjects.

5. Use only a currently approved consent form, if applicable.
Note: Approval periods are for 12 months or less.

6. Protect the confidentiality of all persons and personally identifiable data, and train your staff and collaborators on policies and procedures for ensuring the privacy and confidentiality of subjects and their information.

7. Submit a Continuing Review Application for continuing review by the IRB. Federal regulations require IRB review of on-going projects no less than once a year a reminder letter will be sent to you two months before your expiration date. If a reminder is not received from Office of Research Support (ORS) about your upcoming continuing review, it is still the primary responsibility of the Principal Investigator not to conduct research activities on or after the expiration date. The Continuing Review Application must be submitted, reviewed and approved, before the expiration date.

8. Upon completion of the research study, a Closure Report must be submitted to the ORS.

9. Include the IRB study number on all future correspondence relating to this protocol.

If you have any questions contact the ORS by phone at (512) 471-8871 or via email at orsc@uts.cc.utexas.edu.

Sincerely,

James P. Wilson

James Wilson, Ph.D.
Institutional Review Board Chair

Appendix B

BACKGROUND INFORMATION

1. What is your present marital status?
   1 Never Married
   2 Married
   3 Divorced
   4 Widowed
   5 Separated
   6 Living with a significant other

2. What is your present employment status? (Please circle only one choice.)

   1 I work full-time for pay (Includes farm/ranch work)
   2 I work part-time for pay (Includes farm/ranch work)
   3 I am a full-time homemaker
   4 I am a full-time homemaker and also help with farm/ranch work
   5 I am a full-time homemaker and also work part-time at another job
   6 I am unemployed due to age
   7 I am unemployed due to disability
   8 I am laid off
   9 I have been fired
   10 I am a full-time student
   11 I am a student (full- or part-time) and also work for pay
   12 I have been unable to find suitable work because of where I live
   13 I am retired

3. What is your age?(Year 3) _____

4. How many years of school have you completed? (Year 7) _____

5. What is the highest degree you have completed?
   1 No degree
   2 Vocational Training or Certificate
   3 GED
   4 High School Diploma
   5 Associate Degree
   6 Bachelors Degree
   7 Graduate Degree (Masters or Doctoral)

BACKGROUND INFORMATION (Continued)

Please answer BOTH questions

6. Are you Spanish/Hispanic/Latino?

_____ No, not Spanish/Hispanic/Latino

_____Yes,, I am Spanish/Hispanic/Latino

7. Which of the following best describes your race?
(You can circle more than one answer)

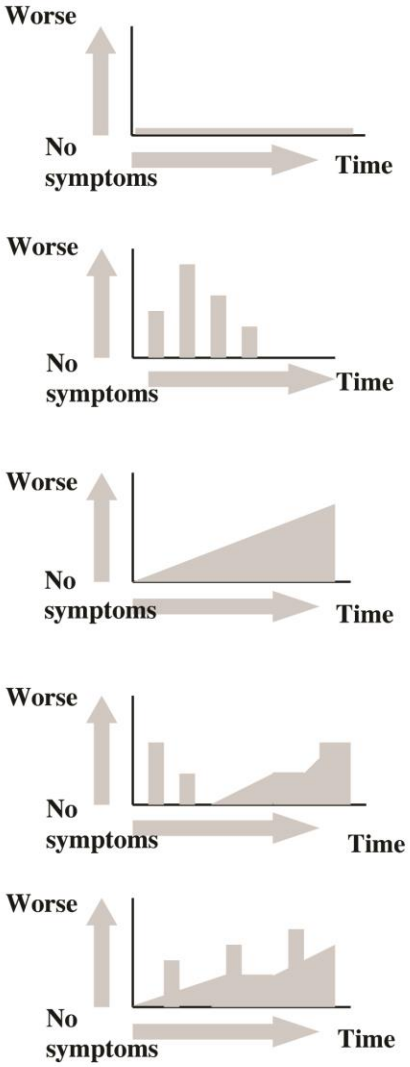
1 American or Alaska Native
2 Asian
3 Native Hawaiian and other Pacific Islander
4 Black, African American, or Negro
5 White
6 Other (Please describe) _____

Please answer the following question by placing a check next to the answer that you think best describes your own health.

MS PATTERN

The following questions are about your MS, your symptoms and your treatment.

1. MS tends to take different clinical courses. Which type best describes your experience with MS?



1. Benign Sensory MS: Attacks are characterized by sensory symptoms and/or optic neuritis, but usually no long term severe disability.

2. Relapsing-Remitting MS: Symptoms fluctuate (come and go) over time. There are clearly defined periods of worsening of symptoms followed by periods of recovery without disease progression over time.

3. Primary-Progressive MS: Symptoms and related disability become more serious over time. There are not distinct periods of remission (symptoms going away) or serious relapse (sudden worsening of symptoms).

4. Secondary-Progressive MS: The disease process starts with a relapsing remitting course, but eventually changes to a continually progressive course.

5. Progressive-Relapsing MS: Symptoms progress from the beginning. There are definite periods of relapse (sudden worsening of symptoms) that may or may not be followed by full recovery.

6. Unable to choose one answer or don't know the type of MS that best describes my experience

ECONOMIC ADEQUACY SCALE

The following are general questions related to the economics of daily living.

1 = Not at all
2 = Less than Adequately
3 = Adequately
4 = More than Adequately

1.	Does your family income allow you to meet your needs for daily living?	1	2	3	4
2.	Does your family income allow you to meet your rent or mortgage payment?	1	2	3	4
3.	Does your family income allow you to meet your food bills?	1	2	3	4
4.	Does your family income allow you to meet health care needs?	1	2	3	4
5.	Does your family income allow you to participate in recreation?	1	2	3	4
6.	Does your family income allow you to meet child costs or the costs of other dependents (skip if no children or dependents)?	1	2	3	4
7.	Does your family income allow you to meet the special needs created by MS?	1	2	3	4
8.	Does your family income allow you to meet other financial needs you have?	1	2	3	4

PERSONAL RESOURCE QUESTIONNAIRE (PRQ-85)

(Brandt and Weinert)

Below are some statements with which some people agree and others disagree. Please read each statement and circle the response most appropriate for you.

1 = Strongly Disagree
2 = Disagree
3 = Somewhat Disagree
4 = Neutral
5 = Somewhat Agree
6 = Agree
7 = Strongly Agree

1.	There is someone I feel close to who makes me feel secure	1	2	3	4	5	6	7
2.	I belong to a group in which I feel important.....	1	2	3	4	5	6	7
3.	People let me know that I do well at my work (job, homemaking).....	1	2	3	4	5	6	7
4.	I can't count on my relatives and friends to help me with problems.....	1	2	3	4	5	6	7
5.	I have enough contact with the person who makes me feel special	1	2	3	4	5	6	7
6.	I spend time with others who have the same interests that I do.....	1	2	3	4	5	6	7
7.	There is little opportunity in my life to be giving and caring to another person.....	1	2	3	4	5	6	7
8.	Others let me know they enjoy working with me (job, committees, projects).....	1	2	3	4	5	6	7
9.	There are people who are available if I needed help over an extended period of time.....	1	2	3	4	5	6	7
10.	There is no one to talk to about how I am feeling	1	2	3	4	5	6	7
11.	Among my group of friends we do favors for each other	1	2	3	4	5	6	7
12.	I have the opportunity to encourage others to develop their interests and skills.....	1	2	3	4	5	6	7

13.	My family lets me know that I am important for keeping the family running	1	2	3	4	5	6	7
14.	I have relatives or friends that will help me out even if I can't pay them back	1	2	3	4	5	6	7
15.	When I am upset there is someone I can be with who lets me be myself.....	1	2	3	4	5	6	7
16.	I feel no one has the same problems as I.....	1	2	3	4	5	6	7
17.	I enjoy doing little "extra" things that make another person's life more pleasant.....	1	2	3	4	5	6	7
18.	I know that others appreciate me as a person	1	2	3	4	5	6	7
19.	There is someone who loves and cares about me.....	1	2	3	4	5	6	7
20.	I have people to share social events and fun activities with.....	1	2	3	4	5	6	7
21.	I am responsible for helping provide for another person's needs	1	2	3	4	5	6	7
22.	If I need advice there is someone who would assist me to work out a plan for dealing with the situation.....	1	2	3	4	5	6	7
23.	I have a sense of being needed by another person.....	1	2	3	4	5	6	7
24.	People think that I'm not as good a friend as I should be.....	1	2	3	4	5	6	7
25.	If I got sick, there is someone to give me advice about caring for myself.....	1	2	3	4	5	6	7

INCAPACITY SCALE

Please circle the response that best describes you in each following question.

1. Are you able to walk up and down a flight of 12 steps?

   0 Without holding onto anything or anyone
   1 With some difficulty but without any mechanical or human assistance
   2 With some difficulty with a cane, brace or prosthesis
   3 With some difficulty--must have human assistance
   4 Unable to go up or down stairs without a mechanical lift

2. Are you able to walk on level ground indoors or outdoors some 50 meters (or approximately 50 yards)?

   0 Without difficulty
   1 With some difficulty but without any mechanical or human assistance
   2 With some difficulty with a cane, brace, or prosthesis
   3 With some difficulty--must have human assistance or a wheelchair
   4 Unable to walk this distance

3. Are you able to enter and leave a regular chair or wheelchair, get on and off a toilet, and get into and out of bed?

   0 Without any difficulty or aid
   1 With some difficulty but without any mechanical or human assistance
   2 With some difficulty with adaptive devices such as a sling, bars, sliding board
   3 With some difficulty--must have human assistance
   4 Must be lifted or moved completely by another person

4. With regard to your bowel function (<u>circle all that apply</u>):

   0 Never experience loss of bowel control
   1 Experience constipation that requires me to eat a high fiber diet or give myself laxatives or suppositories
   2 Experience constipation that requires laxatives, enemas, or suppositories, administered by others
   3 Experience occasional loss of bowel control
   4 Experience frequent loss of bowel control

5. With regard to bladder function (circle all that apply):

   0 Never experience loss of control of your urine
   1 Experience occasional problems with having to go in a hurry or not being able to start or maintain the stream of urine
   2 Experience frequent problems with having to go in a hurry or not being able to start or maintain the stream of urine
   3 Use a catheter or hand pressure to empty the bladder
   4 Experience occasional loss of bladder control
   5 Experience frequent loss of bladder control

6. Are you able to bathe yourself?

   0 Without any difficulty or aid
   1 With some difficulty, but without any mechanical or human assistance
   2 With some difficulty -- need adaptive devices such as a sling, lift, shower, or tub bars
   3 Must have human assistance in bathing or in entering and leaving the tub or shower
   4 Must be bathed by another person

7. Are you able to dress yourself?

   0 Without any difficulty or aid
   1 With some difficulty, but without any mechanical or human help
   2 With some difficulty--use specially adapted clothing or devices dress self
   3 With some difficulty--must have human assistance
   4 Must be dressed almost completely by another person

8. Are you able to care for your teeth and hair, shave and/or apply cosmetics?

   0 Without any difficulty or aid
   1 With some difficulty, but without any mechanical or human assistance
   2 With some difficulty, must have mechanical assistance
   3 With some difficulty, must have some human assistance
   4 Almost all of these tasks are performed by another person

9. Are you able to feed yourself (circle all that apply)?

   0 Without any difficulty or aid
   1 With some difficulty, but without any mechanical or human assistance
   2 With some difficulty with adaptive devices such as special feeding utensils
   3 With some difficulty--must have some human assistance
   4 Unable to eat solid food--have tube feedings performed by self
   5 Unable to feed myself at all

10. With regard to your vision, do you experience (circle all that apply):

    0 Normal Vision: Can read print finer than standard newsprint with or without corrective lenses
    1 Cannot read print finer than standard newsprint with corrective lenses or has occasional double vision
    2 Magnifying glass or large print needed for reading
    3 Double vision that interferes with everyday activities
    4 Only able to read very large print such as major newspaper headlines
    5 Unable to read very large print

11. With regard to your speech and hearing, do you experience:

    0 No difficulty with speech or hearing
    1 Some difficulty with speech or hearing that does not interfere with communication
    2 Deafness requiring a hearing aid and/or difficulty speaking interferes with communication
    3 Severe deafness requiring sign language or lip reading or severe difficulty with speech that requires sign language or written communication
    4 Severe deafness and or difficulty with speech – am unable to communicate

12. With regard to your physical health, how much treatment do your medical conditions (including MS and any other conditions) require:

    0 No significant medical treatment
    1 Medical conditions requiring maintenance medication, but monitoring from physician is not required more often than every 3 months
    2 Medical conditions requiring occasional monitoring by the physician or nurse, more often than every 3 months, but less often than weekly
    3 Medical conditions requiring regular (at least weekly) attention from a physician or nurse
    4 Medical conditions requiring daily attention by a physician or nurse

13. Are you currently experiencing any problems such as feeling sad, nervous or tense, rapid mood swings, or fits of anger?

    0 No problems
    1 Some problems with mood; not interfering with daily functioning
    2 Problems with mood interfere with daily functioning but I manage without professional assistance except for visits to maintain medication
    3 Problems interfere with daily functioning and I must have frequent professional assistance (psychotherapy, hospitalization)
    4 Even with medication and other interventions my mood problems are so severe that I am unable to function

14. Are you currently experiencing any problems such as difficulty remembering things, or problems in counting or calculating?

    0 No problems
    1 Some problems but they do not interfere with day-to-day functioning
    2 Problems interfere with daily functioning; sometimes need to use lists or other prompts
    3 Problems interfere with daily functioning and I must have assistance to perform everyday activities
    4 Difficulties preclude the performance of most of my everyday activities

15. To what extent do you experience fatigue?

    0 No fatigue
    1 I experience fatigue but it does not interfere with my physical functioning
    2 My fatigue causes only mild or passing problems
    3 My fatigue causes frequent problems
    4 My fatigue is severe enough to interfere with prolonged physical activity

16. With regard to sexual functioning (<u>circle all that apply</u>):

    0 I am as sexually active as before I had MS
    1 I have experienced some changes in sexual functioning
    2 I am concerned about changes in my sexual functioning and/or activity

Please answer these questions regarding mammograms by putting a √ check mark by your response(s):

1. Have you ever had a mammogram (x ray of the breast)?
   _____ 1Yes
   _____ 0No
   _____ 2Don't know/Not sure

If **Yes**: Please continue with the following question.
If **No** or **Don't Know/Not sure**: Please skip to question #5 on the next page.

2. How long has it been since you had your last mammogram?
   _____ 1Within the past 12 months
   _____ 2Between 1 and 2 years
   _____ 3More than 2 years ago
   _____ 4More than 5 years ago

3. How often do you **usually** get a mammogram?
   _____ 1Every year
   _____ 2Every 2 years
   _____ 3Less frequently than every 2 years

4. Do you think you need a mammogram every year?

   _____ 1Yes
   _____ 0No
   _____ 2Don't know/Not sure

5. What kind of insurance coverage do you have? (Check all that apply)

   _____ 1Private (e.g. Blue Cross/ Blue Shield, PPO, HMO)
   _____ 2Medicare
   _____ 3Medicaid
   _____ 4Other (Please describe:) _____
   _____ 5No insurance

6. Has anyone in your immediate family (mother, sister) ever had breast cancer?
   _____ 1Yes
   _____ 0No

7. Do you have difficulty standing for 20 minutes?
   _____ 0Not at all difficult
   _____ 1A little difficult
   _____ 2A great deal of difficulty

Breast Cancer Screening Belief Scales for Women with Chronic Disabling Conditions (BCSBSWCDC)

The following questions ask about your thoughts and feelings about breast cancer screening (mammograms) @V. L. Champion, Breast Cancer Screening Belief Scales, 1999. Used with permission from the author for modification.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
MAMMOGRAMS:					
1. When I get a recommended mammogram, I feel good about taking care of my health.	1	2	3	4	5
2. When I get a mammogram, I don't worry as much about breast cancer.	1	2	3	4	5
3. Having a mammogram or x-ray of the breast will help me find lumps early.	1	2	3	4	5
4. Having a mammogram or x-ray of the breast will decrease my chances of dying from breast cancer.	1	2	3	4	5
5. Having a mammogram will help me find a lump before it can be found by myself or a health professional.	1	2	3	4	5
6. Having a routine mammogram or x-ray of the breast would make me worry about breast cancer.	1	2	3	4	5
7. Having a mammogram or x-ray of the breast would be embarrassing.	1	2	3	4	5
8. Having a mammogram or x-ray of the breast would take too much time.	1	2	3	4	5
9. Having a mammogram or x-ray of the breast would be painful.	1	2	3	4	5
10. Having a mammogram or x-ray of the breast would cost too much money.	1	2	3	4	5
11. Having a mammogram or x-ray of the breast would be difficult because of lack of transportation.	1	2	3	4	5
12. Having a mammogram or x-ray would be difficult because it is hard to get positioned for the mammogram machine.	1	2	3	4	5
13. I feel it is likely I will get breast cancer in the future.	1	2	3	4	5
14. I am more likely than the average woman to get breast cancer.	1	2	3	4	5
15. I don't think about getting breast cancer because I feel I already have enough to deal with.	1	2	3	4	5

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Vita

Ana Teresa Todd was raised in a culturally enriched home in Rochester, New York with a Venezuelan mother and a Belgian-American father, in which only Spanish and French were spoken in the home. She obtained her first bachelor's degree in Psychology from the College of the Holy Cross, after which she worked at Northeastern University in Boston, Massachusetts as a counselor coordinating co-op placements for undergraduate students. Following completion of coursework in the MBA program at Northeastern University, Ana realized her passion for nursing and obtained her bachelor's degree in nursing from Fitchburg State College in Fitchburg, Massachusetts. Ana's nursing career began in women's health and newborn care. As a clinical nurse, she also worked as a Parent Educator, teaching about infant care and breastfeeding in English and in Spanish. Her interest in women's health shifted to a public health focus while working as an outreach liaison for a breast center. Her interest in teaching and research motivated her to pursue her Ph.D. in nursing at The University of Texas at Austin. During her Ph.D. program she was fortunate to have the opportunity to work as a research assistant under an NIH diversity training supplement under Dr. Alexa Stuifbergen in her longitudinal study on health promotion in persons with MS, which inspired her to focus her research interest in mammography among women with a chronic disabling condition. Her research interest has also been inspired by her personal experience with living with functional limitations

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